MANUAL FOR CBR PLANNERS

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FOREWORD

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There then follow 5 sections about needs assessment and suggestions of how to understand local communities and how to encourage community participation in CBR programmes.

The final 6 sections are concerned with programme management issues for example, organising self help groups, training personnel for CBR and issues around the sustainability of projects including evaluation and management of change.

This manual will be helpful to planners and managers of CBR programmes and it is to be hoped that it will receive wide distribution and readership among practitioners. It would be a lost opportunity if this manual remained unused on the shelves of national organisers rather than being on the desks of local planners and managers of CBR programmes.

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1 COMMUNITY BASED REHABILITATION HISTORY, CONCEPTS & CURRENT UNDERSTANDING

Community based rehabilitation (CBR) has been in existence for some time now. During the earlier years, the pace of growth and changes in this field were fairly slow. In the last few years however, development and changes have been significant, and the field of CBR today is understood in a vastly different manner from what it was in the initial years.

Understanding of CBR in the Eighties

Although different forms of non-institutional rehabilitation were known to exist some centuries ago, community based rehabilitation gained formal recognition and world-wide acceptance only with its promotion by World Health Organisation and other UN agencies in early eighties. It was since promoted as a suitable method to rehabilitate people with disabilities living in developing countries, who hitherto had had no access to services. Since developing countries had limited resources to provide extensive coverage of high quality services for their disabled citizens, the emphasis was on evolving a method that would provide wide coverage, at costs that were affordable to governments of these countries. Implementation of this method involved shifting rehabilitation interventions to homes and communities of people with disabilities, to be carried out by minimally qualified non-professionals such as families and other community members, thereby reducing costs of setting up expensive institutions.

The evolution of CBR in developing countries was in total contrast to development of rehabilitation in developed world. Developed countries already had good coverage of high quality rehabilitation services, and organisations of disabled persons in these countries launched the "Independent Living (IL)" movement to take control of programmes related to their concerns, on their own. This stance was in response to what many disabled people perceived as 'professional control and dominance' over their lives, which they sought to overthrow. Thus the independent living movement was an attempt at ownership of disability related programmes by persons with disabilities themselves, while CBR was promoted in response to needs of governments and disabled persons in developing countries for coverage of services at affordable costs.

In the early eighties, CBR was conceptualised and evolved primarily as a service delivery method with a medical focus, since WHO had recommended that it be integrated into primary health care system that was already well established in many developing countries. The International Classification of Impairments, Disabilities and Handicaps (ICIDH) published in 1980 by WHO also contributed to a medical approach. ICIDH defines a model that progresses from disease, impairment and disability to handicap in a linear fashion. Impairment is defined as abnormality of structure or function of the body or an organ. Disability is defined as a restriction or lack of ability as a result of impairment. Handicap is defined as a social disadvantage faced by an individual resulting from either impairment or disability. With these influences, early CBR programmes tended to have an 'impairment' bias, focusing on prevention of impairments and restoring functional ability in disabled individuals in order to 'fit' them into their community.

Changes in Understanding of Cbr in the Nineties

During eighties and nineties there was tremendous growth in number of CBR programmes that were promoted in different developing countries, mainly by international donors. Many of these were micro projects with limited impact, that could not be replicated or grow into viable national programmes. Along with quantitative growth in CBR programmes, there were changes in the way it was conceptualised. One of the early changes was the shift from a medical focus to a comprehensive approach, with the realisation that medical interventions alone did not complete the rehabilitation process. Thus CBR programmes also began to address comprehensive interventions such as education, vocational training, social rehabilitation and prevention. The other major change was a shift in focus from restoration of functional ability in an individual, to modifying community attitudes and contextual factors. The understanding was that it was not enough to merely change an individual to 'fit' him into the community, but that it was equally important to change contextual factors around the individual, as he/she does not live in isolation, but in the context of his/her own community. Along with this came the recognition that CBR also needs to include different issues related to disabled people's lives at all times, and not focus exclusively on rehabilitation. Changes in contextual factors involved changing attitudes of non-disabled persons in the community to accept people with disabilities and promote their social integration, provision of equal opportunities in education, employment and so on, to the same extent that they were available to non-disabled persons, protection of rights of disabled persons, and promoting community control and ownership of CBR programmes.

These changes during the last decade were reflected in various ways, at different levels, across different countries. The first was the change in definition of CBR, from a service delivery approach to a community development one, as reflected in 1994 joint

position paper of WHO, ILO and UNESCO. According to this definition, "Community based rehabilitation is a strategy within community development for rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through combined efforts of disabled people themselves, their families and communities, and with appropriate health education, vocational and social services". Many people accept this as a working definition. It moves away from the idea that CBR is merely a form of 'therapy in community', whereby services shift their geographical location 'to the community', but retain practices that are used in an institutional or clinical setting. In such community-based therapy, disabled people and their families remain passive recipients of services, with professionals retaining control. The community development approach on the other hand, promotes community participation and community ownership of programmes, with the active involvement of disabled persons and their families in all issues of concern to them instead of being passive recipients. It also recognises that disabled people should have access to all services which are available to other people in community, such as community health services, child health programmes, social welfare and education.

Another reflection of these conceptual changes is the revision of ICIDH in 1999. ICF (International Classification of Functioning and Participation) avoids the term 'disability' because it indicates a negative connotation and has replaced it by 'activity'. 'Handicap' is replaced by 'participation' to indicate the person's nature and extent of involvement in life situations in relation to impairment, activity and contextual factors. 'Contextual factors' are extrinsic factors that play an important role in determining participation. ICF covers three dimensions of functional state, namely, function and shape of body, activity and participation. Classification of function also includes mental functions. `Impairment' is a problem of function or shape of body. The second dimension is 'limitation in activity' which reflects the difficulty an individual has in performing a task or an activity, formerly 'disability'. There are qualifiers to indicate degree of difficulty and assistance required to overcome the difficulty. The third dimension is 'restriction in participation', formerly 'handicap'. It exists when an individual has problems in participation in one of the life domains, due to either his impairment or because of environmental factors that commonly impact on participation. Unlike ICIDH, emphasis has shifted from the individual alone to include the context around him. This classification is not linear and emphasises influence of the health condition and contextual factors simultaneously on impairment, activity and participation.

The third significant change is promotion of equal opportunities and protection of rights of persons with disabilities by many governments in developing countries during the last decade. For example in South Asia, Sri Lanka, Bangladesh and India have enacted legislation to protect the rights of disabled persons.

Yet another reflection of these changes is the growth of organisations of persons with disabilities in many developing countries. Some of these countries have established national affiliates of the Disabled Persons' International, one of the major proponents of independent living movement from the West. These organisations have been active in all areas, including service provision, information dissemination and advocacy. Many have been instrumental in lobbying with governments to enact legislation to protect their rights and to bring about changes in existing laws to prevent discrimination against disabled persons.

CBR in 2000 and Beyond

The beginning of the new millennium coincides with the beginning of evidence based practice in CBR. Early decades of the millennium will be a phase of consolidation for CBR. As CBR expands from small to large programmes, research will become the engine to drive new initiatives. Unlike in small programmes, sole reliance on past experience will be insufficient to initiate, maintain and achieve goals of large programmes. Hence great importance will be given to policy development, planning and monitoring in future. Good systems, efficient structures and tangible results will become preconditions for funding large projects. Pressures to follow internationally accepted good practice rules would also become more prominent than earlier. On the whole, CBR will consolidate into a better defined, more accepted framework of development for people with disabilities, within which wide contextual flexibility is permitted for each programme's structure and systems.

These changes in approaches are likely to make programming a crucial aspect of any new initiatives in CBR. However, community programming will require adopting a 'bottom-up', participatory approach rather than the prevailing institutional 'top-down' coercive approach. After all, members of the community are less likely to be coerced to accept a plan they do not approve, unlike their counterparts in institutions.

Definitions of CBR

Rehabilitation as an organised programme started with segregation of disabled people from others who were not disabled. In course of time, welfare services were provided by charitable organisations for disabled persons out of pity for their state of isolation. These services were primarily individual focussed, medically oriented and institutional in nature, where disabled persons received services passively. As time progressed, these services became highly technical and excellent in quality, though ownership was with the providers. The relationship was 'provider-beneficiary'.

With the human rights movement becoming prominent, many changes were to follow in the field of disability rehabilitation. These included 'Independent living movement'

that professed complete ownership of all aspects of management of disabled persons by themselves. This view supported the concept of 'Empowerment' of disabled individuals. The second major change was planning of interventions directed at the community where disabled persons lived, to create a barrier free environment for disabled persons. Also emphasised were awareness creation and special provisions to enable equal access for disabled persons to all services in the community. In this phase of development, the emphasis was on a social model of rehabilitation as against the medical model in the past. The relationship thus changed to 'provider-client'.

Today, the main goals of rehabilitation have become broader than earlier, and focus beyond the individual, to his community where he is being integrated. Thus, the universal mission of CBR may be expressed as

1. To enhance activities of daily life of disabled persons,
2. To create awareness in disabled person's environment to achieve barrier free situations around him and help him attain equal human rights,
3. To create a situation in which the community of the disabled persons, participates fully and assimilates ownership of their integration into his society. The relationship here is 'client-owner'.

Current Common Usage of the Term 'CBR'

1. Home based services provided by families to their disabled members in their homes.
2. Self help projects run by disabled persons.
3. Out-reach projects run by rehabilitation institutions.
4. NGO projects run by paid CBR workers.
5. An ideology, which promotes inclusion of disabled persons in developmental projects.
6. Institutional programmes located in villages.
7. A term to describe anything related to rehabilitation of disabled persons.

The term CBR is thus assigned to numerous concepts. Many authors have tried to classify these different concepts into common groups based on different dimensions, and have tried to identify programmes that are similar to each other. However, most of these tools used for classification of CBR groups have been difficult to apply. Yet, one way of grouping CBR programmes that are relatively similar, is to look at goals they are expected to achieve.

1. How much do they enhance activities of daily life of disabled person?
2. How much do they create awareness in the disabled person's environment to achieve barrier free situations around him and help him attain equal human rights?
3. How much do they create a situation in which the community of the disabled person participates fully and assimilates ownership of his integration into his society?

If these questions can be rated quantitatively by assigning a figure, it can be used for classifying programmes into groups according to the strength of their goals A description of familial and community factors that interfere with full participation will also help in identifying contextual barriers during planning.

Classification of Disability Related Organisations

1. Service providers.
2. Foreign donor organisations.
3. National donor organisations.
4. National organisations for disabled people.
5. National associations of disabled people.
6. Self-help groups related to disabled persons, such as 'parent's group'.
7. National community development organisations.
8. Others.

The Future

Despite the shifts and changes, many questions and issues remain about CBR. These questions are critical for policy makers and planners to address before CBR can be implemented effectively.

What Does Programme Planning Mean in CBR?

Many community based rehabilitation programmes are carried out by voluntary organisations in the non-governmental (NGO) sector. A close look at some of these programmes shows that they originated as a set of activities without clear goals, and have continued without long term plans. Some programmes were started because of the availability of designated funds for that particular activity at that point in time. With shifts in donor priorities, activities of some of these organisations changed according to availability of funds. These programmes often did not have monitoring and evaluation systems, nor did they define their outcomes or attempt to measure them. Instead,

they repeated a set of activities year after year, with some illustrations and anecdotes from their clients, to justify why they had to continue their activities. Such activities tended to be donor dependent, cost-intensive, seldom successful, rarely sustained once the donor withdrew support. Therefore, they often became counterproductive to efforts of local communities in developing more appropriate; grass root led rehabilitation services. Consumer satisfaction was also limited, as client needs were rarely taken into account for these activities.

Programme planning is a crucial component of development activity, but it is by no means synonymous with the preparation of the initial project proposal to fulfil donor requirements. Unlike what is often claimed, it does not also result in curtailment of creativity in a programme. On the contrary, it enhances creativity, and if channelled adequately, it increases effectiveness. It also does not mean that planned programmes cannot be initiated in response to sudden needs for interventions, as in disaster relief. In any on-going programme, it is necessary to have clear goals and a set of actions for it to be successful.

In the pre-policy stage, one needs to determine if disability is perceived as a 'problem' that needs intervention on a priority basis in the target community. This is followed by a current situation analysis, that helps to confirm whether there is need for intervention, what priority consumers assign to the proposed problem in relation to other problems, whether consumers view the proposed intervention as beneficial to them in addressing their problem, and so on.

Successful completion of the pre-policy stage usually progresses to policy development, which includes defining vision, mission and objectives of a programme. These components of policy are best evolved in a participatory and democratic manner involving all stakeholders of a programme, rather than by any particular group. A participatory process of policy development will help avoid future conflicts and enhance collective action. Once a policy is formulated, it requires to be widely disseminated amongst all stakeholders and other associates of the project. Most organisational members are usually able to articulate their organisation's vision and mission well, but have difficulties in clearly stating their objectives and activities. They often describe numerous objectives that are over-inclusive, without considering whether it is feasible for the organisation to fulfil them at all, in the available time. Sometimes activities are confused with objectives and vice versa, which results in poor strategic plans. Quantitative target setting is rarely followed in most poorly planned programmes.

Selection of activities and formulation of a strategic plan are usually the responsibility of executives of the programme, and are executed with approval of the governing body. Individual activities that are components of a strategic plan are short term in nature, usually planned for the duration of a calendar year or a financial year. In order

to monitor programmes easily, activities need to be defined precisely, with well defined, quantitative targets of achievement for each activity in a unit time. Expected outcomes, indicators to measure them and to measure resultant impact are also required to be defined clearly. Organisations usually enumerate their activities with quantitative measures of coverage, in the belief that they can represent outcomes and impact. However, without outcome and impact measures, it is impossible to know if a programme has been genuinely successful. Although some effort is required to develop a detailed strategic plan with well-defined activities, targets, expected outcomes and their indicators, such a process can be of significant benefit to a programme in many ways. It helps the organisation to monitor and control progress of their efforts easily, to clearly define individual responsibilities of programme personnel, and to make programmes transparent and accountable to stakeholders.

Who Should Initiate CBR? People from Outside? Or the Community?

In earlier years when CBR was a form of service delivery, this question was irrelevant. Today however, CBR is viewed as a development process, and the question of whether CBR should be imposed by outsiders or initiated by community, is debated widely.

In the earlier years, CBR tended to be a form of 'community therapy', where services were physically shifted to the community, but clients remained as passive 'beneficiaries'. Subsequently it has changed to a community development programme where disabled persons and their families were actively involved in all issues of concern to them, with the ultimate goal of gaining full ownership of their programme. 'Community participation' is conceptualised today in the social model as a central and essential tenet of CBR. In practice, however, most CBR programmes find it difficult to achieve this goal.

Usually one assumes that communities are homogenous, cohesive and mutually supportive entities, but in reality, it does not appear to be so. They are, in most instances, quite heterogeneous, with wide differences in socio-economic status, educational status, religion, ethnicity and so on. This diversity sometimes causes friction, because different groups in a community have widely differing needs and priorities, and usually others do not consider the needs of disabled persons who are in a minority, as a priority.

Given this background, how does one define the 'community' in a CBR programme? Does it comprise only of people with disabilities and their families who are in a minority and are primary clients, or is it larger community that may not want to share its resources with disabled people?

In developing countries, poverty is a major barrier to participation in development programmes, as people have other pressing needs to fulfil before they can own their

programmes. Corruption and cornering of wealth by vested interests is another issue that mitigates against participation by all. People in developing countries also have difficulty in operationalising decentralisation and 'bottom-up' practices due to a cultural reluctance in people to take charge of their own affairs. Because local communities usually expect benefits from Government as permanent doles, they also resist taking charge of their programmes on their own.

Consequently, the issue for debate among planners today is whether CBR should be initiated in a community by an external agency, or should one wait for local communities to start CBR on their own? Votaries of the former opinion advocate starting services for disabled individuals without waiting for community participation, as it may take a long time, and in the meantime the needs of many disabled persons would remain ignored. They argue that community ownership of programmes, where people take on responsibility for planning, implementing, sharing risks of and monitoring their programmes, is unlikely to be achieved in the foreseeable future. There is also a suspicion in the minds of many people that governments as a ploy to abdicate their responsibility, use the rhetoric of 'community participation', because taxes collected are spent on causes other than development.

The opposing argument is that CBR is a developmental issue and as such, it needs to be initiated by concerned groups themselves, who in this case are people with disabilities and their family members. If externally initiated, clients will continue to remain passive recipients of services, with expectations of charity, and without initiative to manage their own affairs and to contribute to society.

Since people in developing countries are largely ignorant about consumer ownership of development programmes, it is not feasible in most instances to begin programmes with full ownership by communities. There is however, a possibility of striking a balance between these two opposing arguments. CBR programmes will need to motivate the local community to participate in their development to begin with, and over time, to also shoulder the responsibilities. In this process, the community will gradually acquire management skills to take over their programmes as well.

Does The Social Model Ignore 'Real Rehabilitation' Needs of People with Disabilities?

When WHO initially promoted CBR, it was designed to be integrated into PHC system. Hence many early CBR programmes followed a medical model, which came in for criticism in the eighties as not being sufficiently sensitive to all needs of people with disabilities. As a result, most CBR programmes that evolved subsequently as separate programmes addressed an array of needs, in a comprehensive manner. The perception then was that unless a special focus was given to disability, 'specialised' needs of

people with disabilities would remain unmet. However, with the shift from a medical model to the social model, the emphasis today is on integrating disability into development processes. According to votaries of this model, it is more cost-effective, and promotes better social integration by ensuring that people with disabilities have access to same benefits and services as others in the community, unlike a 'specialised' CBR programme that concentrates on people with disabilities and may actually isolate them from the mainstream. Besides, community participation is likely to be greater in a programme that benefits the majority, rather than a minority group. At the same time, people fear that unplanned integration of disability into other development programmes can ignore 'real rehabilitation' needs, such as mobility, special education, vocational rehabilitation and so on. In turn, this can contribute to increased marginalisation of people with disabilities, rather than their integration into the mainstream.

The last few years have witnessed attempts to integrate disability into community development projects that showed some tangible benefits for disabled people from integration. Many problems were also encountered in this process. Lack of organisational ability and knowledge about disability on the part of community development organisations acts as a major barrier to integration. Disability is seen as a 'specialist' issue, and hence these organisations feel that they do not have the expertise to deal with it. Further, disabled people tend to be recognised only by their disability and not by any other parameter such as gender, poverty level, ethnic status and so on, resulting in their exclusion from benefits of integration in a development programme. Lack of mobility, education and skills in disabled people prevents them from being part of development programmes, while expectations of charity and poor motivation on the part of disabled people also contributes to their exclusion.

Integration of disability issues into development programmes implies a high degree of co-ordination and collaboration between different sectors such as health, education, employment and so on. Often, such co-ordination works better at local, 'grass-root' levels, but fails at higher regional or national levels. Difficulties in multi-sectoral collaborations can be due to many reasons. In developing countries, programmes tend to be 'porous' and as a result, different players in the field take time to trust each other. Secondly, there are differences in the management cultures of government organisations and non-governmental organisations (NGOs), with government operating in a top-down manner while NGOs are usually 'bottom-up' and democratic in their management style. These differences can become a barrier to effective collaboration. Thirdly, under cover of 'collaboration', members often try to gain control over each other rather than work towards a common goal, and hence multi-sectoral collaborations get submerged in power and control issues between different sectors. Lack of commitment to the goal from all partners can also be a problem in multi-sectoral

collaborations. Usually, a powerful minority controls the process while rest are passive participants. As a result, in many instances decisions are finalised by a minority and the majority is made to merely endorse them.

Many of these issues will need to be resolved before a social model can become effective. Until such time however, it may be more realistic to pursue a plan that is most feasible in a given context, focusing on the goals of the programme as the central issue at all times.

Is CBR Inexpensive? If so, for Whom?

CBR was promoted to achieve wider coverage, at costs that are affordable. This was to be achieved by shifting rehabilitation interventions to families of disabled persons, thus reducing expenses on institutions and personnel, and consequently reducing unit costs of rehabilitation. The question is, who carries the burden then? Although CBR programmes appear to be cheaper because of home based interventions, in reality, costs to consumers in terms of their efforts, time and money, may turn out to be much higher than what it is generally believed to be.

The point then is, whether consumers are ready to take on additional burden of costs of CBR interventions. Secondly, even if they are willing to do so, can they afford to do so? Many families in developing countries who are struggling for their daily survival, feel that it is a waste of effort and money to address rehabilitation needs of their disabled children, preferring instead spend on other children without disability in the hope that they would support them in their old age. In an environment of increasing competition for resources, their reasoning is that unless other children are well placed, they may not be in a position to support their disabled sibling in future, especially since few protective social security schemes are available in these countries. Until some of these issues are addressed, it is unlikely that consumers would be ready to bear costs of rehabilitation on their own.

Is CBR The Answer for All Disabled People or Only For A Select Few?

It is estimated that 70% of people with disabilities could be handled at the community level, while the remaining 30%, comprising of people with severe and multiple disabilities would require specialist interventions that are not available at the community. Evaluations of CBR programmes in eighties and early nineties endorsed this view. With the change towards a social model that emphasised equity and integration, CBR as it evolved subsequently began to address the need to include all people with disabilities within its ambit of services and interventions. In reality, however, the desired level of equity has not been achieved, leaving out some sections of people with disabilities.

It is estimated that about 20% of the disabled population that requires interventions from a CBR programme are people with severe disabilities, many of whom would also have multiple disabilities. In poorer communities, the percentage of people with severe disabilities is low, as families may not seek help for their survival. In some communities, mortality of children with disabilities reaches almost 80%, leading to a 'weeding out' phenomenon. However small their number may be, CBR programmes face many difficulties in dealing with severe disabilities.

External agents, who need to show quick results in their programmes, work with mildly and moderately disabled persons and thus build a rapport with the community. As a result, people with severe disabilities tend to be left out of interventions. Most CBR programmes also do not have personnel who are adequately trained to deal with this group. Sometimes, in the process of promoting 'community participation' and 'rights' of disabled persons, severely disabled persons get neglected. As yet, there are no valid methods to effectively address needs of this group at the community level.

Women with disabilities are another group whose needs are not adequately addressed by CBR programmes, particularly in traditional cultures. Although disability leads to segregation of men and women, women with disabilities face certain unique disadvantages, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services which are dominated by male service providers. Concerns of women with disabilities also tend to get neglected in organisations of people with disabilities that are usually dominated by disabled men. Even women's organisations in developing countries consider these women as disabled first and as women only secondarily. CBR programmes will need to develop appropriate strategies to address issues related to traditional, social and cultural perceptions. Strategies such as awareness building to dispel misconceptions about disabled women's gender roles, skills development training and home adaptations, creation of educational and employment opportunities, training of women CBR staff, and sensitisation of women's organisations and disabled persons' organisations to include issues of women with disabilities in their agenda, can help to reduce inequality between men and women with disabilities.

Can Volunteers in CBR 'Afford' To Volunteer?

In an international workshop on CBR in 1998, participants from twenty-two CBR projects were asked to identify major challenges facing them. Almost all participants identified problems linked to community volunteers as one of the significant issues. The problems had to do with difficulty in finding new community volunteers, fast turnover of volunteers, need for additional resources for continuously training new volunteers, lack of motivation among volunteers and need for paying incentives or small salaries to volunteers.

The role of community volunteers is perceived as one of the major issues for CBR projects in different parts of the world, particularly in the light of current emphasis on 'community participation'. There are examples of CBR programmes that have successfully used volunteers, but these are probably the exception rather than the rule.

The point of debate is, can there be true voluntarism in developing countries where a majority of the population cannot afford to 'volunteer'? The dictionary definition of 'volunteer' is a person 'who voluntarily expresses a willingness to undertake a service while having no legal concern or financial interest'. Though the term 'volunteer' is used often in CBR, in reality it covers a variety of identities and roles that do not confirm to the definition of the term. Some persons may have enough time to dedicate to their chosen task, others may have some time during specific periods of the month or the year, and a few may be available only for a limited period of time. With the adoption of market oriented economies in many developing countries during the last decade, people require paid employment for their survival and are therefore less willing to volunteer. Those who do volunteer often use their training and experience as a stepping stone to paid employment later. Under these circumstances, it is not always realistic to expect voluntary work for long periods of time at the same quality as paid workers.

Do We Recognise The Importance of Cultural Factors in CBR?

Cultural factors play a very important role in determining our behaviour in day to day life. These factors influence our attitudes towards most of the happenings around us, including 'disability'. Community based rehabilitation is context dependent, and terms such 'handicap' and 'participation', the most relevant parameters in rehabilitation, are defined in relation to contextual factors that are predominantly cultural. 'Cultural factors' in the broad sense are a set of variables related to tradition, ethnicity and religion, grouped together into a single entity, that influence participation of disabled persons in their milieu. Even across populations of a single country, there are substantial differences in ethnicity, caste, religious practices and so on, which are recognised by different laws applying to different groups within the same nation. What seems to be ethnically correct behaviour in one group of people, may not be recognised as such by a different cultural group. Recognition of these differences in the perception of 'normalcy' and 'disability' is very important in case of rehabilitation, since what is considered a 'handicap' in one cultural context may not be considered so in another context.

The influence of cultural factors is so great, that many community based rehabilitation interventions fail as a result of poor recognition of these factors. Yet during the planning stages of programmes, most projects recognise culture as only an insignificant

determining factor that influences success. For example, Western stereotypes of 'community' are often used during planning of community based rehabilitation programmes in developing countries, where communities have their own individuality that is different from Western norms. These programmes expose themselves to a higher risk of failure because they tend to conflict with cultural factors of the host country. The concept of individual rights and empowerment, as expressed and understood in the developed world, does not exist in many developing countries. Traditionally in these countries, an individual belongs to a kinship group, with a network of relationships and mutual obligations. Because of this kind of relationships, the concept of empowerment for many individuals, whether disabled or not, is more complex than in the developed world. In many Asian countries, 'empowerment' of an individual as understood in the western context, is seen as selfish and undesirable. Being altruistic for the sake of family and larger society has higher value. Hence an individual tends to remain role-bound, submissive and obedient, and conformity with traditional systems becomes a virtue. In these societies, 'empowerment' can at best be interpreted as a right to access provisions and services on an equal footing as others. Similarly, women in many traditional societies remain segregated from men, and 'integration' of disabled women into the 'community' is perceived in a different manner from west. In such societies, disabled women can be integrated into a community of segregated women, but they may need to remain separate from men.

Rehabilitation is a gradual and long process that cannot escape influences of local cultural factors, particularly because decentralisation of services into community, and integration of disabled persons into their society, calls for closer attention to cultural factors. There is enough evidence from literature to suggest that culturally appropriate community based rehabilitation programmes can be practised in many traditional societies by appropriately adapting strategies to make programmes suit the given cultural context. It is very important for community based rehabilitation planners to give adequate emphasis to these factors during policy development and planning, to avoid high risk of later failures.

What is The Role of Evaluation and Research in CBR?

Over the last 2 decades, CBR has gained acceptance as the preferred approach of service delivery for people with disabilities in developing countries. However, many questions remain about CBR. There is little published literature about different aspects of CBR, including cost effectiveness or cost benefit, as in other areas such as community development, primary health care, and so on. There are still many different interpretations of CBR, making it difficult to compare different programmes. There has been little research on outcomes, and little effort to develop indicators with which to measure success. Many evaluations of CBR programmes continue to remain as

mere descriptions of practice and of perceptions of different stakeholders about the programme.

More rigorous evaluation of CBR and indicators to measure outcomes of CBR are vital if the field is to grow and develop further. CBR managers, field workers and professionals need to show benefit of their programmes. Without this, governments and policy makers would find it difficult to justify increased allocation of resources for CBR programmes.

Of late, different groups, working in Canada, Netherlands and UK, have started stressing the need for more rigorous evaluations, evidence based practice and development of appropriate indicators to measure success. It is generally accepted that new indicators must be user-friendly for all stakeholders and be related to goals of the programme. However, it is also difficult to develop indicators that are acceptable to a range of researchers involved in disability issues with different underlying philosophies.

Some groups working on indicators have published lists of possible indicators that could be used in future evaluations. If indicators are to be used to determine effectiveness of programmes at field level and to inform future planning, they need to be used by service providers in their programme evaluations as part of their work. Field testing across different cultures may also help to determine which indicators could be culture-free and which are culture-dependent.

People involved in disability programmes especially in developing countries are still not sufficiently aware of the importance of evidence based practice, which is gaining ground in the fields of health and development. Donor agencies, policy makers, programme implementers and user groups increasingly require evidence of value for money, value for input and value for effort. Evidence based practice requires clear statements of activities, outcomes and indicators. In a field like community based rehabilitation, that has grown mostly based on experiential accounts over last two decades, a move towards evidence based practice is vital at this point in time, if interest in this field is to be sustained.

Conclusion

After more than two decades of CBR in different parts of the world, many people believe that it is an appropriate approach for people with disabilities in developing countries. But many controversies and questions remain unanswered. If sufficient attention and resources are allocated to research, it is possible that some of these questions may be answered in the coming decade.

Points for Discussion

1. How would you describe the relationship of your programme personnel with disabled persons in your CBR programme? As 'provider - beneficiary', 'provider - client', or 'client-owner'?
2. What are the family and community barriers ('contextual factors') that prevent participation of disabled persons in community activities in your CBR programme?
3. Would you describe management of your CBR programme as 'top-down' or 'bottom-up'? Why?
4. How would you classify your CBR programme, based on its goals?

2 COMMUNITY BASED REHABILITATION PLANNING

DIFFERENCES BETWEEN INSTITUTIONAL AND COMMUNITY BASED REHABILITATION

REHABILITATION IN INSTITUTIONS	
Merits	**Demerits**
Aims to reduce effects of impairment	Coverage restricted to surrounding areas
Good infrastructure and systems	Disabled people become segregated from families and need to access services at the providers' level
High degree of technical skills, high end equipment and personnel	
High degree of predictability and controls, hence monitoring is easier	Results are dependent on good infrastructure, technology and professionals
High acceptance, especially from non-disabled persons	Costs are high, because of high-end infrastructure, equipment and personnel
Interventions for acute and immediate post-acute phases in most cases	Systems developed by top-down and coercive methods increase dependency in clients
	Methods used can be inappropriate for a given community setting
	People expect permanent solutions or 'cures' from rehabilitation in institutions

Merits	Demerits
Aims to integrate people into society	Structures and systems are largely amorphous
Meets needs of all disabled persons, with comprehensive interventions	Multiple and multi-sectoral resources have to be co-ordinated to function cohesively
Encourages innovative use of local resources	Acceptance occurs late because of locally adapted technology, less trained personnel, slow results, low literacy and superstitions
Increases coverage, because interventions are decentralised	People have to be well organised before collective action can be initiated in the community
Promotes integration because of the need for the community to organise	No universal models are available to easily replicate from one setting to another
Changes negative attitudes of community	Social, economic, cultural, geographical and political environment in some areas may not yet be conducive to initiating CBR
More affordable to those with limited resources	Inadequate knowledge and skills in the community on planning and development
More flexible and creative, depends heavily on needs and resources of the community	Communities resist changing beliefs and practices in disability and rehabilitation
Promotes community participation in planning, developing and monitoring the programme	Lack of infrastructure, functioning institutions and social organisations in villages

Planning for programmes in community is different from planning for programmes in institutions. Communities usually do not have ready-made structures and systems to implement a new programme, unlike institutions. Hence, new programmes have to be developed from grass-roots in a 'bottom-up' manner. Communities have to be organised to initiate a participatory process to develop collective and consensual strategies. In institutions, the members can be coerced to follow a top-down strategy, while in community based programmes, members have to be persuaded to accept a strategy before they follow it. Community based programmes, unlike institutional programmes, are not easily controlled, and consequently the end results are less consistent.

Differences Between Planning for CBR in Urban Communities and Rural Communities

Much of the available information on CBR is based on rural communities. However, there are differences between rural communities and poor urban areas, that have to be considered before planning for community based programmes in urban areas.

Characteristics of urban poor communities	Characteristics of rural communities
Floating population, due to seasonal migration from villages	Relatively fixed population with little migration
More heterogeneous, with differences in language, religion and culture, due to the migratory population	Relatively homogeneous communities, with similar background and characteristics
Community is dependent on unskilled labour of different types	Rural communities are largely dependent on agrarian economies
Mainly unitary, nuclear families	Rural communities are often clusters of extended and joint families
Population density is high	Population density is low, tends to be sparse and scattered over larger areas
Formal or informal leadership structures change frequently and are not permanent	Often has more permanent formal and informal leadership
Community organisation can be difficult, as the community can be politically sensitive and are used as 'vote banks'. Hence climate of suspicion and expectations of doles are high	Community organisation can be easier because of a relatively more open and welcoming climate in rural societies

'Community' interested in urban CBR tends to be mainly mothers of persons with disabilities	'Community' in rural CBR includes members of the general community who are not directly related to people with disabilities
Social problems are greater in urban poor communities	Social problems are relatively less in rural communities
Availability of services is high, but access is low because of poor affordability, lack of social supports and so on	Availability of services is low, but access to the available services is better than in urban communities

Wherever a programme is being planned, it is important to follow a participatory system of planning involving all stakeholders, in the interests of better effectiveness and sustainability. Unless the community accepts the programme strategies, they are likely to discard them. Coercing stakeholders to follow a new strategy does not ensure its acceptance.

Steps of a Planning Process

Components of a Policy

Vision: Vision is the ultimate goal of the programme for as long as the programme lasts

Mission: Mission is the sum of all activities to achieve the vision.

Vision and mission are timeless, concise and brief expressions of the sum of objectives of a programme.

Objectives: Objectives are medium term directions towards achieving the vision.

They are evaluated periodically and changed if necessary at the end of each phase.

SEQUENCE OF MANAGEMENT ACTIONS TO DEVELOP A NEW PROGRAMME PLAN

STEPS	WHAT	BY WHOM
PRE-POLICY STAGE		
Problem identification	Identification of disability as the priority	1. Donor, GO, NGO etc 2. Community / Client Promoter
Situation analysis	1. Literature review 2. Needs and resources analysis	
POLICIES		
Vision	Long-term end results (Goals)	Stake holders :1 Donors 2. Practitioners 3. Clients
Mission	Long-term methods to achieve the goals	Stake holders :1 Donors 2. Practitioners 3. Clients
Objectives	Medium -term directions	Stake holders :1 Donors 2. Practitioners 3. Clients
ACTIVITIES		
Short term	Well defined, quantifiable, measurable, with outcome indicators, targeted for completion in a unit time	Programme staff With approval of the governance
Medium term	Well defined, quantifiable, measurable, with outcome indicators, targeted for completion in a unit time	Programme staff With approval of the governance
Long term	Well defined, quantifiable, measurable, with outcome indicators, targeted for completion in a unit time	Programme staff With approval of the governance

BUDGET

Income	Activity-wise Short term, Medium term, Long term	Sources Short term, Medium term, Long term
Expenditure	Activity-wise Short term, Medium term, Long term	For what 1. Recurring / Manpower / Material/Technology 2. Capital

PROBLEM IDENTIFICATION

PLANNING

IMPLEMENTATION

PROCESS EVALUATION

IMPACT EVALUATION

BACK TO PROBLEM IDENTIFICATION

Points for Discussion

1. **Who are the important stakeholders of your programme?**
2. **State the vision and mission of your CBR programme.**
3. **State the most important objective of your CBR programme.**
4. **Define one activity that fulfils the objective you have stated.**
5. **What is the target for completion of this activity in the current year?**
6. **What are the short term and long term outcome measures for this activity?**
7. **What is the budget estimated for this activity in the current year?**
8. **How will you monitor this activity?**

3 COMMUNITY BASED REHABILITATION NEEDS AND RESOURCES ANALYSIS

NEEDS ANALYSIS

CBR interventions influence lives of disabled persons, their families and their non-disabled peers. Hence it is necessary to identify needs of all these different groups before undertaking strategic planning of CBR programmes. Different groups could have differing needs. Needs may not also necessarily be related to priorities identified by external technical experts. By prioritising a list of needs, different groups express what needs are most important for them. Often the priorities of a CBR programme as whole, with a mix of short-term, medium-term and long-term strategies, may differ from some of the constituent stakeholders' list of priorities. Many consumers of services tend to prioritise short-term goals, while technical experts tend to prioritise long-term goals. When there are wide differences between the needs of different constituent groups and they are different from programme priorities, the first strategy is to reduce the gaps through concomitant change in attitudes to bring about acceptance of common priorities. For this purpose, the existing beliefs and attitudes of different constituent groups need to be identified and modified.

Needs analysis is usually carried out as a pre-planning/pre-proposal exercise by initiators from within local community, such as community institutions, family groups or self-help groups of disabled persons, who initiate CBR programmes, or by outside experts such as governmental agencies, donor organisations or catalyst NGOs.

STEPS TO BE CARRIED OUT IN ASSESSING NEEDS

1. WHAT ARE THE EXPRESSED NEEDS OF THE CLIENTS, THEIR FAMILIES AND THE COMMUNITY?
2. WHAT ARE THE PRIORITIES OF THE CLIENTS, THEIR FAMILIES AND THE COMMUNITY NOW?
3. WHAT ARE THE EXISTING BELIEFS AND ATTITUDES RELATED TO REHABILITATION IN THE COMMUNITY?
4. HOW DO DIFFERENT GROUPS ESTIMATE THE EFFICIENCY OF EXISTING REHABILITATION SERVICES IF ANY?
5. WHAT ARE THE LACUNAE IN EXISTING REHABILITATION SERVICES?
6. WHAT CHANGES DO THEY FEEL ARE NECESSARY IN THE EXISTING SERVICES TO MAKE IT BETTER?

Points for Discussion

1. **What would you do if the priorities of the community as a whole were different from needs of disabled people in your CBR project area?**
2. **What would you do if needs of disabled persons, their families and local community in the project area are different from priorities mentioned by technical experts in your project proposal?**

Resource Analysis

A strategic plan/proposal will have to also identify and assess existing resources available to the project from the project area, their efficiency and their shortcomings. The availability of each resource (financial, personnel, material and technical) and their accessibility have to be estimated during the pre-planning stage.

RESOURCES ANALYSIS FOR CBR

Availability

1. Availability of funds.
2. Support of the community for the CBR programme.
3. Availability of technical information on CBR.
4. Availability of trained personnel to carry out CBR interventions.
5. Availability of family volunteers to care for disabled persons.
6. Availability of institutional and professional support for CBR.
7. Availability of efficient planning and administration for the CBR programme.
8. Availability of infrastructure at reasonable cost.
9. Availability of aids and appliances for rehabilitation.

Accessibility

1. Free accessibility.
2. High motivation to give.
3. Proximity to the CBR programme.
4. Reasonable cost.
5. Who grants permissions to avail resources?
6. Awareness about available resources for use by the CBR programme.

Name of the resource	Is it Available for CBR?	How easy is to access it?	How do you improve access?	What modifications are required before the resource is used?	How much does it cost for modification?	What is the recurring cost if the resource is used?

Points for Discussion

1. What are the useful resources that you can identify from your CBR project area?
2. Can you explain how you will modify and use one of the resources that you have identified for your CBR?

4 COMMUNITY BASED REHABILITATION ADDRESSING NEEDS OF WOMEN WITH DISABILITIES IN CBR

Although there is a world-wide trend towards women with disabilities emerging from their isolation to establish their own self-help groups and rights groups, the situation in developing countries remains quite different. There is less research on issues facing women with disabilities in developing countries, even though the majority of women with disabilities live in these countries. Available literature on women with disabilities in developing countries often states that these women face a triple handicap and discrimination due to their disability, gender and developing world status. Gender equity is an issue for a large majority of women in developing countries, given the socio-cultural practices and traditional attitudes of society. Therefore, many of the issues faced by women in general in a male dominated society, such as limited access to education and employment, problems arising from traditional cultural practices that tend to seclude women from public life, and so on, have a greater impact on women with disabilities. Although disability leads to inequality and marginalisation of both men and women, disabled people from both sexes do not form a homogenous group. Women with disabilities from developing countries face certain unique disadvantages compared with disabled men. In many developing countries, poverty can exacerbate these disadvantages, by limiting access to resources and to rehabilitation services.

TRADITIONAL GENDER ROLES

For men and women, expectations of gender roles are different, especially in traditional societies, where each sex is expected to perform different roles in society, according to different criteria. These roles are determined by historical, religious, ideological, ethnic, economic and cultural factors. In these societies, men are expected to work outside the house, earn a living and support a family, while women are judged according to their physical appearance, and their ability to look after a home, their husband and children. Traditionally, women are expected to take the responsibility for all domestic chores such as cooking, cleaning, marketing, fetching water or fuel, washing clothes and utensils, entertaining visitors, overseeing celebrations of events or religious ceremonies in the house, and so on.

A statement made by Manu, an ancient lawmaker of India, reflects the status of women in this region: 'In childhood a woman must be subject to her father, in youth to her husband and when her Lord is dead, to her son. A woman must never be independent'.

Although society's view of women has come a long way from the time of Manu's law, in most traditional societies, the roles of wife and mother continue to be the most important roles assigned to women. These roles give women in these countries a special status in society. A woman is revered as a mother if she has sons. Any woman who is unable to fulfil these roles is viewed by society as a useless person.

Disability can have a profound impact on an individual's ability to carry out traditionally expected gender roles, particularly for women. Although both men and women with disabilities would face difficulties in fulfilling their expected gender roles, as long as a disabled man earns a living, his chances of getting married and having a family are much more than those of a disabled woman. A disabled woman tends to be judged and found wanting in appearance, in comparison with the conventional stereotypes of 'beauty' in her culture. She is perceived as one, who is unable to perform her traditional roles of wife, mother and homemaker because of her disability, even if she may be able to do so in reality. For example, a woman with mobility impairment may be perceived as one in need of physical assistance in self-care and grooming, and therefore unable to carry out domestic tasks requiring mobility and physical labour.

Some studies report that women with disabilities are less likely to be married than disabled men. This is largely due to negative attitudes and stereotypes about what disabled women can or cannot do, particularly in societies where elders arrange marriages and it is a contract between the concerned families rather than individuals. Many people have the misconception that because of her physical disability, a woman may not be competent in any sphere, and that a physically disabled woman is also unable to think, learn or work. In addition, because there are few positive role models for women with disabilities, many myths prevail about them. Women with disabilities also have less chances of meeting potential marriage partners, because of restricted mobility and freedom. In a few instances, disabled women may be married off by their families to 'wrong' persons, such as men who are already married, so that families can 'get rid of the burden' of caring for them. There may be higher demands for dowry in case of a woman with disability. Women with disabilities are also more likely to be divorced or abandoned than non-disabled women, because of perceptions that a disabled woman is helpless, unable to care for her family, and unable to contribute to family's economy.

Childbearing, like marriage, is considered as the natural destiny of every woman in many traditional societies. Being childless is considered to be a great misfortune, for which the woman is usually held responsible. Women with disabilities face specific attitudinal barriers in this regard. They are perceived as being in need of care themselves, because of their disability, or the common belief is that looking after children requires physical fitness and mobility, which disabled women may lack. Because of

these reasons, women with disabilities are perceived as being unable to fulfil a caring, mothering role. Additionally, there are misconceptions about the disability being inherited by children. Women with disabilities also have less access to information and health care services about their special needs in relation to pregnancy and childbearing.

Women with disabilities face difficulties in carrying out many of the domestic chores that are normally expected of a woman in traditional societies, or they take longer to perform the tasks, or require some assistance in doing so. However, because of their disability and restricted mobility, society considers them as ill suited to perform the role of home-maker, since they are perceived as helpless persons who are unable to perform the required tasks independently.

Access to Rehabilitation Services

Women with disabilities generally have less access to rehabilitation services than disabled men. In accordance with traditional social and cultural norms in village societies, many women do not go out of their houses to seek help for health care, especially if the care-provider is a male. Most rehabilitation personnel, including community based rehabilitation workers in developing countries are men. Thus even home based services provided by male CBR workers, are out of reach for many women with disabilities. Strangers, even if they are part of a service provider team, are usually not allowed inside a house in traditional societies. If these strangers are male, it is next to impossible for them to even talk to women in the house. Even if a traditional community accepts males as service providers in health care and rehabilitation to some extent, it still would be impossible for them to provide services to, or teach women in the community. Such a situation can only be improved if local women were to be trained as rehabilitation workers. While women rehabilitation workers are beginning to be seen more commonly in CBR programmes, cultural barriers continue to persist, preventing women from taking up rehabilitation work in a community setting, because it involves visits to houses of strangers.

These two factors, namely, preponderance of male rehabilitation workers and relative absence of trained women workers in a community setting, are major barriers faced by women with disabilities in developing countries from accessing rehabilitation services. In the case of fitment of mobility aids in particular, women with disabilities experience a unique difficulty. A large majority of people with disabilities, many of whom are women, requires mobility aids because of polio and other physical disabilities. However, most trained technicians in orthotics and prosthetics are male, and women with disabilities

who require mobility aids are unable to access services from male technicians due to cultural taboos related to being examined by men.

Women with disabilities also have less access to other health care, education or vocational training opportunities than disabled men. But this situation is common to women in general in traditional societies in the sub-continent, where women's health needs are usually relegated to the last place in the hierarchy of family needs, where women's education is considered as an 'unnecessary luxury', and where women are not expected to go out and work to earn a living. Hence problems of access to services is not unique to disabled women.

Participation in Community Life

Women with disabilities tend to have fewer opportunities to participate in community life than disabled men, mainly due to cultural reasons. Restricted mobility and absence of access provisions in the surrounding environment can also be a hampering factor in participation of women with disabilities in community life, but this aspect is common to disabled men as well.

The families of disabled women tend to be over-protective about them, and prevent them from going out of the house, for fear that they may be exploited in some way because of their disability. Although well intentioned, these anxieties can be stifling to women with disabilities. There are superstitions in some village communities about the presence of disabled women being inauspicious in community gatherings. It is also believed that their presence in a family can block chances of marriage for their female siblings. As a result, many women with disabilities remain confined to their parental homes, without being able to play roles traditionally expected of women in society. This can lead to feelings of isolation, loneliness and low self-esteem in women with disabilities. Families in traditional societies are generally supportive in terms of physical assistance to their disabled women, but often fail in providing emotional support, which is a more complex issue. Many families prefer to ignore the existence of feelings, emotions and the need for emotional support in women, especially if they are also disabled.

In recent years, many self-help groups and associations of people with disabilities have been established in most countries in the sub-continent, but women with disabilities are under-represented in these groups. Leadership in disability groups at various levels tends to be dominated by disabled men. Likewise, women with disabilities are hardly represented in the women's movement that has grown in these countries over the last decade, because they are seen as 'different' or 'disabled', and not as 'women'. As a result, concerns that are unique to women with disabilities have tended to remain neglected by both the disability movement and the women's movement.

Exploitation and Violence against Women with Disabilities

Women with disabilities tend to be more vulnerable to exploitation of various kinds, such as sexual harassment, domestic violence and exploitation in the workplace. It has been found that women with disabilities are twice as prone to divorce, separation, and violence as able-bodied women. Disabled women also tend to be relatively easy targets of sexual exploitation, particularly if they are mentally retarded. In general, disabled women tend to be in a state of physical, social and economic dependency. This can lead to increased vulnerability to exploitation and violence. Because of the relative isolation and anonymity in which women with disabilities live, the potential for physical and emotional abuse is high. It is also estimated that having a disability doubles an individual's likelihood of being assaulted. Because of their isolation however, women with disabilities are likely to have less resources to turn to for help.

Strategies to Address Needs of Women with Disabilities

While women with disabilities form an important sub-group in most CBR programmes, usually there are no strategies that are specially tailored to address the unique disadvantages that they face. However, in some countries such as Pakistan and Afghanistan, the need for culturally appropriate services have been recognised, and these services are being provided within the prevalent 'purdah' culture, for women with disabilities and for female carers of children with disabilities. In these societies, where women are segregated from men, there are specially planned, women-orientated programmes being carried out. Examples of such interventions are training of women service providers, and carrying out camps, workshops and seminars exclusively for women by women. These programmes take special care not to contradict the prevailing cultural norms of behaviour.

Although some western experts believe otherwise, promoting individual rights amongst women with disabilities in a 'purdah' culture, so that they can access services alongside disabled men, may not succeed easily. The reason is that Asian women would prefer to conform to traditional norms of societies in which they live, rather than break away from them, because of a higher value placed on 'collective submission' in these societies. Any individual who attempts to break free of these norms may be seen as the 'odd one out' who disrupts group harmony.

Many of the unique disadvantages faced by women with disabilities are related to traditional social and cultural perceptions and beliefs. In this context, CBR programme may have to address some of the complex cultural, economic and social factors that are related to expectations from traditional gender roles.

Awareness Building and Attitude Change

Public education and awareness building efforts about the potential of women with disabilities with appropriate interventions, would have a role to play in removing misconceptions about marital, domestic and motherhood roles, and in bringing about changes in attitudes. Efforts have to be made to build up positive role models of women with disabilities who are able to fulfil their family roles, in order to change the myths and misconceptions associated with their ability to carry out these roles effectively in the community. Such role models are important to make the community understand that given appropriate interventions, women with disabilities would be in a position to shoulder family responsibilities and also contribute to family economy.

Developing Positive Role Models

CBR programmes will need to focus on training of young disabled women through home based training or through peer support groups to focus on grooming, self care, domestic, physical and social skills, in a one-to-one setting or in groups where feasible. Through these efforts, positive role models of disabled women would become available in the community, and act as motivators for other disabled women and their families.

Support Services

Issues regarding fertility and childbirth in case of women with disabilities may need specialist referral to medical services. Since women with disabilities have difficulty in performing some domestic tasks or may need to perform them differently, CBR programmes will need to explore how best to support them in carrying out some of these household tasks, through simple adaptation of the home and the surrounding environment. Adaptation of homes and surroundings can be carried out through assistive devices like low trolleys and so on, that are more appropriate in rural households where many tasks like cooking and cleaning tend to be performed at ground level.

Access to Rehabilitation Services

Lack of access to rehabilitation services by women with disabilities can be overcome by training more women community workers to provide services. While availability of trained women workers in community based rehabilitation programmes has improved in many countries today, one area where women with disabilities continue to face difficulties is fitment of appliances, where technicians are predominantly male. This is a major deterrent to the achievement of mobility by women with disabilities. Most training institutions in orthotics and prosthetics also have not recognised this problem

sufficiently. However, of late, there have been innovative attempts to address the issue by training disabled women as technicians to provide mobility aids for women with disabilities. These efforts will not only improve access to services, but also improve mobility in disabled women, which in turn can help to foster positive attitudes about their capabilities and roles in the community.

Promoting Self-Reliance Through Education and Employment Opportunities

Providing girls and women with disabilities with better educational and employment opportunities will serve to improve their situation by reducing their dependence on their families and providing them with opportunities for self-reliance. A study in China has shown that education of disabled women was closely related to marriage and chances of employment. Increased opportunities gave women more self-confidence and better social positions, increasing their chances of getting a life partner.

Promoting Self-Help Groups

Promoting self-help groups of women with disabilities will play a major role in reducing their isolation, providing mutual support, and improving their participation in community life. It can promote economic self-reliance if they have access to income generation activities through savings and credit and other schemes. Being economically self-reliant will give a woman with disability an added advantage in marriage and allow her to contribute to the household economy. Promotion of self-help groups will also help to reduce over-protection by families. In addition, self-help groups can educate women with disabilities about their rights and opportunities, and greatly reduce chances of exploitation and violence against them.

Inclusion in Disability Groups and Women's Groups

CBR programmes need to sensitise disabled persons' organisations and women's groups, to include concerns of women with disabilities in their agenda. As an initial strategy, it may be helpful to promote groups of women with disabilities, to educate them about their rights, and to build up their capacity for advocacy and lobbying. Alongside, efforts will have to be made to include women with disabilities in larger disability groups and in women's groups.

World-wide, women with disabilities are emerging from their secluded state and addressing their concerns by organising themselves, and forming their own self-help and rights groups. In developing countries, there are a few women with disabilities who have overcome prejudices and negative social attitudes to become role models for others. Some countries have formulated policies relating to health care, education and rehabilitation to include women with disabilities. Many non-governmental

organisations in these countries are also beginning to include issues facing women with disabilities into their agenda. However, women with disabilities continue to face problems related to access to opportunities, negative attitudes and environmental barriers, which are problems that all disabled persons face. These barriers coupled with some of the unique disadvantages that women with disabilities face in traditional societies in developing countries, have contributed to keeping them marginalised, preventing them from taking their rightful places in these societies. However, it is possible to bring about a change in their situation through specially planned CBR programmes, to overcome the disadvantages that they face and to make them integrated, contributing members of their societies, with the same opportunities and choices as anyone else.

Points for Discussion

1. **What are the important needs of women with disabilities in your programme?**
2. **What are the unique disadvantages faced by women with disabilities in your programme?**
3. **What strategies will you plan to address the needs of women with disabilities in your programme?**

5 COMMUNITY BASED REHABILITATION INNOVATIVE USE OF LOCAL RESOURCES

The Oxford dictionary defines the term 'innovate' as 'bring in novelties' or 'make changes'. In the context of community based rehabilitation (CBR), innovation would mean unusual or creative ways by which resources of the community can be utilised to carry out rehabilitation in homes of people with disabilities rather than in institutions for rehabilitation. Few people however, recognise the importance of innovation in CBR. The basic assumptions of CBR are that a majority of rehabilitation interventions can be shifted to homes of disabled people, hence coverage can be increased at a cost that is cheaper, by using local resources. The methods used for this transfer cannot be standardised to suit every situation where CBR is practised. Hence, each programme will have to create its own 'novel' method that is appropriate and effective for itself. Hence practitioners of CBR need to be creative at all times, unlike those who work in institutions where practices are standardised rather than flexible.

The very concept of CBR is an 'innovation'. Faced with diminishing resources, most developing countries were forced to find an affordable alternative to expensive institution based rehabilitation, and to provide better coverage better than institutions. CBR was promoted to address this need. Rehabilitation interventions are shifted to homes of disabled people in CBR, to be carried out primarily by their families. It is assumed that rehabilitation interventions of a reasonable quality can be satisfactorily provided for a majority of people with disabilities, at an affordable cost, in this manner. Families, after brief training, with some funds, and the use of available local resources, could carry out interventions on their own. If it is feasible for interventions to be thus shifted to homes of disabled persons, coverage of rehabilitation services could increase tremendously, with minimal additional expenditure that most developing countries could afford.

There are however, many questions related to the actual implementation of CBR. One question pertains to the ability of relatively less educated family or community members to be trained in a short time to carry out rehabilitation interventions in a totally non-standardised and unstructured environment. Many formats describe training methods of varying duration and curricula, to transfer rehabilitation skills to different levels of CBR personnel in the community. But the effectiveness of these methods is uncertain.

Another universal issue is that CBR carries out interventions using methods and materials that are unique and appropriate to only its given context. Structured and

standardised interventions applicable in institutions use more permanent infrastructure and methods. At the community level, standardised intervention techniques, infrastructure and tools are not always appropriate. Hence, CBR personnel need to use creative problem solving methods for CBR interventions. While using creative methods, use of locally available resources is also of great importance. It is only through use of local resources that CBR can become more effective and affordable. CBR personnel are therefore expected to acquire rehabilitation skills in the short period of training and further follow it up by innovations at work.

For easier understanding, local resources can be broadly classified into personnel, materials, skills and finances. For rehabilitation interventions in the community to reach optimum effectiveness, it is necessary to use all these resources in an innovative way. In the context of CBR, the term 'optimum' would mean the best possible outcome at an affordable cost in a given situation. Innovations using local resources in CBR therefore need to reduce costs, improve outcomes and make rehabilitation interventions more appropriate to given context.

There are many examples of significant innovations in CBR from different parts of the world. An outstanding example that received international acclaim is the development of the 'Jaipur Foot' in India. In the example of the 'Jaipur Foot', one sees the innovative use of locally available material and manpower, resulting in a more appropriate, acceptable, inexpensive and easily available mobility aid. Local artisans use discarded automobile tyres as raw material for the artificial limb. The advantages are that the aid is cosmetically appealing for people who do not wear shoes, who need to squat often and who work in wet paddy fields or need to climb trees.

CBR literature over the past few years has reported many other innovations in the area of mobility aids, and use of cane and bamboo in rural programmes. Likewise there have been innovations in the area of prosthetic aids. Use of volunteers in CBR is another significant innovation. There are reports from different parts of the world about use of local volunteers as CBR workers for rehabilitation interventions. It is assumed that CBR workers can be recruited from the community and trained effectively. As a result costs can be reduced considerably. However, results from such experiments using volunteers in CBR programmes are still inconclusive.

Some of the examples described above about innovative use of local resources suggest the need for creative thinking in the practice of CBR. The fact that there is no universally applicable standardised model of CBR underscores the necessity for innovations, for programmes to be effective. Hence, it is important for CBR personnel to be innovative in the use of local resources.

Points for Discussion

1. Can you give one example of innovation that you have carried out in your CBR programme?
2. Can you identify a potential innovation that you have not yet carried out and that can make a major change for your CBR programme in the future?

6 COMMUNITY BASED REHABILITATION UNDERSTANDING THE "COMMUNITY"

Definition of "Community"

The word 'community' is derived from its Latin and Greek origins. The Latin word "communitas" means "common". The Greek word "biocenosis" means "a group of integrated and interdependent plants and animals"

Currently, the term "community" has two general meanings. The first refers to 'actual groupings of people' or *'geographical groups'*. The second refers to 'social ideals of solidarity, sharing and consensus' or *'affinity groups'*.

In community based programmes, it is important to define who constitutes the "community", and to determine their level and type of involvement in the programme. Plans for community participation in programmes can only be developed if the nature and meaning of "community" is understood in the given context or setting of a programme.

Community Groupings

Community groupings are usually defined through geography or through affinity.

Characteristics of geographical groups	Characteristics of affinity groups
Physical proximity provides a set of conditions leading to shared interests	Human characteristics such as age, gender, ethnicity, disablement, sexual orientation and so on
There are often wide differences among members in social affinity characteristics such as religious practices, wealth and education	Socially defined characteristics such as education, social class, political affiliation and so on
Since physical proximity increases likelihood of social interaction, individuals may assume a shared set of interests and valuess	The greater the affinity or shared characteristics in a group, the more cohesive the sense of 'community' in group members

COMMUNITY DIVERSITY AND DIFFERENT INTEREST GROUPS

"Natural and homogenous" communities are difficult to find.

There can be vast differences within a community with respect to ethnicity and socio-economic status etc. that can cause problems in co-ordination of services.

There can be vested interests and power structures within a community that corner a majority of benefits.

In many places, "traditional" communities are fast disappearing because of political and developmental trends such as urbanisation, migration, war and conflicts that lead to displaced populations and other such changes.

Powerful positive connotations of the term "community" leads to it being co-opted by interest groups at national and international levels for their own purposes.

Community Values

Value systems followed by communities can also have negative or positive implications for service providers in community based programmes.

Western society values	Asian society values
Individualism	Collectivism
Achievements of an individual's rights is of high value	Harmony with group's collective wisdom is more valued than individualism

Understanding the "Community" in CBR

While issues of defining and understanding the community in which a programme is to be initiated is crucial for any community based development activity, it assumes greater complexity in community based rehabilitation (CBR). In CBR programmes, there are multiple groups with vastly different interests such as persons with disabilities, family members, general community members, associated professionals, government officials, and so on. These groups in turn have widely varying needs, such as functional independence, supportive services, management, resource development and so on. Each group requires unique methods to mobilise them, such as advocacy, self-help,

training, awareness raising and so on. The unique challenge for CBR is to understand and address the breadth of these community interests, needs and mobilisation methods.

Points for Discussion

1. **Who are the constituents of the "community" in your CBR programme?**
2. **Who are different interest groups in this "community" directly involved to your programme?**
3. **What are the major community values that affect disability rehabilitation in your CBR programme?**

7 COMMUNITY BASED REHABILITATION
COMMUNITY PARTICIPATION

Whatever the term 'community' may mean to different people, they understand that changing levels of community's participation to a higher level is indeed difficult. At the level of implementation, relatively small projects that were started in response to the community's needs show higher levels of participation, community ownership and more consensual modes of decision making. However, large projects with extensive service delivery systems that lack client-centred planning, generate little community participation and community ownership. In the latter, no one expects large-scale participation. Non-vocal stakeholders, who often constitute the majority, get 'marginalised' rather than assimilated in them. They perceive themselves as passive participants of the developmental process, rather than as active participants involved in deciding their future. The relationship is `provider-beneficiary' rather than `provider-client' or `client-owner'.

Factors Influencing Community Participation in CBR

Community Diversity

One often assumes that 'cohesive communities' exist in most places, consisting of homogenous groups of individuals who mutually support each other and share collective responsibility. However, experience has shown that it is largely a fallacy, and that communities are really quite diverse. There can be vast differences within a community with respect to socio-economic status, ethnicity, caste, religion and so on, that causes problems in co-ordination of services in the community. There can be many vested interests and unofficial power structures within a community that corner a majority of benefits from the developmental process. Usually, disabled persons who are in a minority in most communities, do not become part of these powerful groups. In many places, 'traditional', benevolent communities have disappeared and are replaced by new communities due to political and developmental trends such as urbanisation, migration, war or natural disasters. Such newly formed communities at times become less supportive and refuse to take up collective responsibility for issues related to their minority groups.

Sometimes, because of powerful positive connotations, the term 'community' tends to get co-opted in reports of interest groups. These groups may then have unrealistic expectations from the community, make plans based on these expectations, and

allocate resources for its development accordingly. For example, in the early years of CBR, UN agencies and governments placed great emphasis on community participation and involvement of disabled persons and their families as a necessary pre-condition for CBR, without considering whether it was feasible or if they were actually ready to participate. Issues related to community diversity and differing interests of different groups were not sufficiently recognised by planners at that time.

Community Values and Culture

Value systems that communities maintain also have implications for service providers in CBR programmes. For example, western society places great value on 'individualism' unlike many Asian societies where greater value is placed on 'collectivism'. In western societies, being able to achieve individual rights is considered as an asset, while in Asian societies, being in harmony with the group's collective wisdom is considered more valuable. These differences in cultural perceptions percolate downwards to many aspects of human behaviour. For example, not questioning authority figures, such as teachers or employers, and conforming to traditional norms in society, are viewed as virtues in many Asian societies.

In many developing countries, traditionally an individual belongs to a kinship group, with a network of relationships that involve mutual obligations. Because of these relationships, the concept of 'empowerment' of the individual in society is complex, regardless of whether one is disabled or not. In some Asian societies, 'empowerment' of the individual as understood in the West, is perceived as selfish and undesirable. Being altruistic for the sake of family or society has higher value than being individualistic. In the Asian context of CBR, 'empowerment' of disabled persons can also be interpreted as a right of equal access to services rather than being individualistic.

Recognition of cultural influences in perception of 'disability' and 'normalcy' is also crucial in CBR, since what is considered a 'handicap' in one cultural context can be considered 'normal' in another. Community based programmes need to recognise these complex cultural factors, perceptions, beliefs and values in order to avoid potential programme failures at a later stage.

Community Needs

Clear definitions and understanding of the 'community', involved in programmes is crucial for success of all development activities. It assumes a greater complexity in CBR where a minority group such as disabled persons is the main beneficiary of the programme. A CBR programme deals with multiple groups with different interests such as persons with disabilities, their family members, other community members,

professionals, government officials and so on. These groups in turn have widely varying needs, such as functional independence, supportive services, efficient management systems, easy access to resources and so on. In planning CBR, it is thus necessary to take into account needs of all different groups. The different needs of these groups may not always relate to the priorities identified during CBR planning. Often CBR programmes have a mix of short term, medium term and long term goals, that are different from priorities of other groups in the community who usually identify short term goals with quick benefits as most important for them. When needs of other constituent groups vary widely from CBR priorities, these differences have to be addressed before CBR is started.

The unique challenge for CBR is to understand and address the breadth of different community interests, needs and mobilisation methods. Needs and resources analysis, that assesses needs of all stakeholders in a programme and identifies all possible resources in the community before the programme is planned, will be of great help.

Barriers to Community Participation in CBR

Although community participation is central tenet in CBR in developing countries, it is not easily achieved. Most programmes have found it difficult to achieve adequate levels of community participation for several reasons, and consequently have continued to maintain 'top-down' management styles that they have been comfortable with.

Many developing countries were under colonial rule before their independence, followed by varying periods of socialistic governance in which the state was viewed as being solely responsible for all welfare and development work. Concepts of decentralisation and bottom up approaches are relatively new in these countries and 'citizenship' as an identity that entails responsibility is not clearly understood. In western societies, communities are more ready and have learned the requisite skills to manage and own development programmes on their own when the opportunity arises. In developing countries however, citizens expect governments to shoulder all responsibilities for the society, and they view efforts to promote community involvement as an abdication of responsibilities on the part of governments. At the same time, many resource-poor governments also transfer costs and responsibilities of development programmes to local communities under the guise of community participation, while the revenue collected is spent on non-developmental activities.

Poverty in rural communities is another major barrier to participation. In these communities, even needs of majority groups have remained unmet. Under these circumstances, majority groups do not readily consider it 'just' to divert resources that they require, to meet needs of minority groups such as disabled persons. There are also small, but powerful groups in the community that often corner benefits from development programmes for their own personal benefits ignoring needs of others. Under these difficult circumstances, 'community participation' where community members take on responsibility for planning, implementation, monitoring and sharing risks, is difficult to achieve.

Planning for Community Participation in CBR

Depending on the cultural context, the optimum level of participation may be viewed differently by different groups. On the one extreme, communities passively participate as a recipient of services, while on the other extreme, participation is viewed as complete ownership of the programme.

Developing countries are still unfamiliar with Western notions of consumer ownership of programmes. Hence it is difficult to begin a programme with full ownership by consumers. CBR programmes need to find ways to motivate marginalised groups of disabled persons, their families, and communities to follow participatory modes of development. Here local communities will assume some of the responsibilities to begin with, and move on at a later stage to take on most of the responsibilities of the programme. Strategic plans have to be developed for CBR programmes to enhance participation from the very inception of the project, keeping in mind the difficulties that may be encountered later.

As in any other strategic plan, enhancing community participation requires clear understanding of prevailing attitudes of people in the community, their current level of participation in programmes and expected level of participation to be achieved in the future. Because of the lack of clarity in concepts, most programmes find it difficult to define levels of participation. Planning for enhancement of participation requires an understanding of the baseline and the expected target to be achieved after a period of time. The table below illustrates a method of grading different levels of participation.

LEVELS OF COMMUNITY PARTICIPATION IN DEVELOPMENT PROJECTS

Level I	Level II	Level III	Level IV	Level V
Community receives benefits from service, but contributes nothing in return	Some personnel, financial or material contributions from community, but no involvement in decision making	Community participates in lower level decisions about daily management	Participation goes beyond lower level decisions to include monitoring and policy making	Programme is entirely run by community members, except for some external financial and technical assistance

Answers to certain key questions regarding existing level of participation, and the project's intentions to enhance participation in future, can give an estimate of how much more needs to be done.

WHAT IS THE CURRENT LEVEL OF COMMUNITY PARTICIPATION?

- What do community members know about the programme?
- How well do they know about the service provider?
- How often do they meet programme personnel?
- What tasks do they carry out on behalf of the programme?
- Do they face any difficulties in undertaking these tasks?
- Do they have any suggestions to improve their participation in the programme?
- Are all sections of the community equally involved in the programme?
- Why are some groups more involved while others are not?

Community participation can also be graded in a quantitative format for purposes of annual monitoring.

QUANTITATIVE ANALYSIS OF COMMUNITY PARTICIPATION

Involvement of the community in	Scores			
	Date	Date	Date	Date
Daily project activities				
Programme administration				
Programme planning				
Taking leadership in programme activities				
Resource mobilisation for programme				
Monitoring and evaluation of programme				
Goal setting for programme				
TOTAL				

Scoring key: No involvement = 0; small involvement = 1; fair involvement = 2; good involvement = 3; excellent involvement = 4

CBR programmes will continue to pay great attention to community participation and ownership as a central issue. However, given the barriers and constraints to participation, it would be unrealistic to expect communities in developing countries to take over and own CBR programmes in the foreseeable future. In these countries, participation and 'bottom-up' management styles can only be brought about by deliberate pre-planned strategies. Although most people feel that it is difficult to enhance community participation in developing countries, a pre-planned method of enhancement can result in better community involvement and sustainability of the programme.

Points for Discussion

1. **What would be the ideal level of community participation in your CBR programme?**
2. **What level of community participation can you achieve realistically?**
3. **What are the barriers that prevent your programme reaching the ideal level?**
4. **What plans do you have to improve community participation in the next 3 years?**

8 COMMUNITY BASED REHABILITATION ORGANISING SELF-HELP GROUPS

Introduction

Over the last two decades, community based rehabilitation programmes for people with disabilities have increased the coverage of services in different countries. Along with service coverage has come the realisation that functional independence alone is not enough. Issues of 'participation', 'ownership' and 'mutual support' are gaining increasing emphasis. The field of disability rehabilitation has thus moved from a medical and impairment orientated activity, to one focusing on rights and group organisation. Of late there is increasing emphasis on issues related to rights of persons with disabilities and on organising them into self-advocacy groups so that they can demand and gain their rights at different levels and on different platforms. Many field level programmes have started organising self-help groups of persons with disabilities and their families, to enable them to access the benefits of developmental processes. However, the process of group formation is a challenging one. In the disability sector in particular, this process has not been studied much or documented.

Why Do Persons with Disabilities get Excluded from the Development Process?

People with disabilities have often been described as the 'hard-core poor' who are rarely included in development programmes, including micro-finance activities. They are often the poorest of the poor in many communities, and therefore the most needy group to be considered in development processes. However, they are also difficult group to carry out interventions for, because of their special needs and attitudinal barriers. As a result, most community development programmes tend to exclude them from their activities. Some reasons for exclusion of people with disabilities from micro credit programmes are:

- negative attitudes and prejudices about credit-worthiness of people with disabilities;
- lack of policies, knowledge and skills on the part of development organisations to include people with disabilities into credit programmes;
- mobility problems of people with disabilities that prevent them from attending meetings;

- low level of education and skills in disabled persons due to their lack of access to these services;
- lack of flexibility in existing credit operations to facilitate inclusion of people with disabilities; and
- expectations of charity and lack of motivation on the part of persons with disabilities and their families.

Hence, context specific strategies will have to be considered by each organisation to include people with disabilities into micro-credit programmes, as many different factors can influence their exclusion in each case.

What is A Self-help Group?

A self-help group is a voluntary association of people that functions democratically and accountably, to achieve the collective goals of the group. Self-help groups are viewed as a possible means to achieve the newly emerging goals of inclusion and ownership in programmes by people with disabilities, and to enhance their participation in the development processes. Organising people with disabilities into self-help groups can serve different purposes depending on the situation and the need. Such a group of people with disabilities can help improve their members' visibility in the community. The members can also support each other through discussions about common problems, share their resources and find solutions together. The availability of an empathetic, supportive group helps people with disabilities in improving their confidence and self esteem.

Characteristics of Democratic Self Help Groups

- Firstly, in such groups, members come together to fulfil a commonly perceived need. The goals of the group need to be clear, known to and shared by all members, and should originate from the needs of the members. An external facilitator can help facilitate formation of a group, but the governance should be the responsibility of its members.
- Secondly, every member in a democratic group has a role to perform and makes decisions in a participatory way to achieve a set of shared goals. This is a difficult phase in the process of group formation and usually takes a long time for completion. In many developing countries people are not familiar with democratic styles of functioning and as a result, power struggles could occur between members of the group and sometimes lead to their fragmentation into sub-groups. In some instances a group is formed after deliberately excluding some stakeholders in an attempt to limit membership and thus reduce perceived threats or competition from others.

- The third important aspect in the formation of a group is the value addition that each member brings to the group in order to achieve the shared goals. This can be estimated by the willingness of members to contribute their share of resources to the group. During this process, those who are not ready to contribute get excluded and it is assumed that their commitment to the goals of the group do not match those of others who contribute.

Therefore it is necessary to spend sufficient effort in the process of group formation before formalisation of self-help groups in order to prevent future disintegration or loss of interest.

The size of the group can vary depending on the need, although homogeneous groups tend to be more sustainable. Self-help groups are also dynamic and their composition changes over time. They usually last as long as the members continue to have commonly perceived needs.

Group characteristics differ in rural and urban areas. In urban areas, people with disabilities and their families usually come together on different occasions to create awareness, improve service provision and support each other. These groups tend to be well informed, have adequate resources, and are able to effectively advocate their causes. In rural areas however, lack of information, awareness and resources are major problems. In such situations, self-help groups are easier initiated with external facilitation, and can be of great help to their members to access the available services.

Challenges in Organising Groups of People with Disabilities

Many difficulties are faced in the process of forming cohesive groups of persons with disabilities. In urban settings, particularly in the lower income sections, group formation can be particularly difficult. People who live in poorer sections of urban areas that exhibit many forms of social discomforts, do not easily trust each other. They often do not have a permanent address, do not easily form human bonding and show less concern for collective causes. The initial time taken for group formation in this context can be quite long.

In rural areas, there are other problems such as distances between clients, and difficult terrain, that can make group formation less practical.

Another problem is the fear that a powerful few in the group will hijack the benefits from others. Also people with disabilities are only a minority in the community, hence their needs are often viewed as a low priority by the rest and they may tend to get marginalised in a group. There are arguments for and against forming groups exclusively of disabled persons and integrated groups with others who are not disabled.

In the former, disabled persons would have the majority voice, but the process may lead to further segregation. In the latter, the process of integration is better, but special efforts are required to ensure that people with disabilities do not get ignored. In order to prevent a few from hijacking the benefits of the group, especially micro-credit activity, time needs to be given for the process of cohesive group formation before initiating credit activities. Groups would also need considerable training and capacity building before they can function effectively and democratically. In such situations, an external facilitator helps to facilitate cohesive and democratic group formation and to carry out capacity building.

Lack of motivation on the part of people with disabilities is another major barrier. Most disabled people are not motivated to form groups to undertake their own development programmes. They expect grants rather than self generated economic development. Many service providers also prefer to give grants because they are easier to administer than economic development schemes, such as credit programmes. As a strategy to enhance motivation, economic development policies of the programme should be explained clearly to all staff and clients even before they are started. Counselling and motivating clients, their families and members of the community, either individually or in groups, will change attitudes that favour charity, towards self-generation of income.

Lack of trust between members and inadequate knowledge of benefits from co-operative enterprises can also be a barrier. Many believe that individual enterprises are better than group enterprises because of lack of trust between individuals. Much time will be needed during the initial stages of group formation to build mutual trust and confidence, and to imbibe the values and benefits of working together in groups for a common enterprise

Organising Self-Help Groups of People with Disabilities

Despite the challenges, self-help groups of people with disabilities are successfully organised in CBR programmes. There are a few pre-conditions that can be of help in organising people with disabilities.

- Meetings need to be arranged in places that are accessible and not too distant from members' dwellings.
- Groups should set the dates for meetings and intimate the agenda earlier, and should discuss matters that concern them directly, such as commonly perceived needs, creation of opportunities, availability of resources and so on.
- A facilitator may be needed in the initial stages to ensure that chosen leaders do not dominate the group.

- Assigning tasks and responsibilities to group members acts as a motivator to keep them involved.

Group meetings can also be used for education and training of members in micro-credit management, administration and leadership skills. Often, groups that start micro-credit tend to focus only on that activity, ignoring all other subjects on the agenda. Facilitators and group leaders need to guard against this practice by assigning separate time for different subjects on the agenda, and including micro-credit as one part of the meeting.

It is easier to organise people who live in permanent dwellings in urban areas, because they do not migrate. In rural areas it is easier to organise those who come from a traditional background with low migration and high affective bonding. Women's groups are generally easier to initiate than those of men. In some areas, it may be possible to organise integrated groups of people with disability along with others, while in other areas, it may be easier to have groups solely of people with disability. The presence of an external facilitator is important, to prevent hijacking of benefits, keep the group motivated, and train them on different aspects of group functioning, especially micro-credit and economic development.

Conclusion

Since group organisation for different purposes is gaining importance in the disability sector, it is important for organisations working in the field to gain a better understanding of the process of group formation. If it is feasible, group organisation would have several advantages. It could be used to initiate micro-credit finance and group pressure could effectively be used to motivate clients to improve their economic development. As a result of group formation, motivation to succeed could also become greater. In some instances, groups could take on the responsibility of monitoring some aspects of the programme. Participation from members of the community could improve, especially if integrated groups are formed. Groups could also function as a platform to create awareness on different issues and for purposes of advocacy.

Points for Discussion

1. **Is it feasible to start self-help groups in your programme?**
2. **What could be potential barriers to formation of self-help groups in your programme?**
3. **What strategies will you follow to form democratic, cohesive self-help groups in your programme?**

9 COMMUNITY BASED REHABILITATION SUSTAINABILITY

Definition of Sustainability

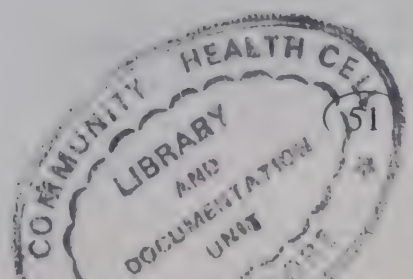
'Sustainability is defined as the ability of a programme to perpetuate itself using appropriate strategies (mission) until its goals (vision) are fulfilled'. Sustainability can also be viewed as 'preservation, perpetuation, or maintenance' of 'vision and mission' of a programme for as long as it is required.

Sustainability is often inaccurately defined as financial ability of the implementing agency to maintain its structure and personnel. Because of this reason, sometimes projects change their goals midway through a programme if they do not get enough funds to sustain their operation. In such an example, organisations are maintained even if they lose sight of their original vision. A CBR programme may thus change into a population control programme if funds for the latter are more easily available.

Phases of Growth of an Organisation

1. **Initial catalyst phase:** Initial 1-2 years of high intensity involvement of initiators.
2. **Growth phase:** Phase of creative expansion of work for 2-3 years.
3. **Crisis phase:** Phase of crisis occurring usually around the 5th year of growth, of mid-course changes in objectives and of conflicts in decision making, that leads to collapse or reorganisation of the programme.
4. **Phase of sustainable growth**: Steady phase of growth that fulfils vision after the initial years of growth and /or crisis.

Many factors influence sustainability of programmes. These factors relate to the external, political or economic situation within which a programme operates, or to internal organisational issues. Community factors can also affect sustainability of a programme. The table below lists different factors that affect sustainability of a CBR programme.



Factors Influencing Sustainability

Components of the system	Factors influencing sustainability	Strategies to improve sustainability
External environment	Political and economic stability Developing policies congruent with national plans Transparency of policies & strategies	Develop valid vision & mission Refer & consult national plans Make clear policies and plans
Organisational environment	Institution building Developing organisational values Developing self reliance	Establish credible governance Establish appropriate legal frame work Establish institutional ethics Transparency of organisational affairs Influence competitors to become collaborators Generate goodwill from community
Organisational Policies	Developing need related policies Developing strategies manageable within available resources Participation of all stake-holders in developing vision, mission and objectives Transparency of policies & strategies Developing valid vision & mission	Institute participatory analysis of needs and resources Literature review, feasibility study before starting the programme Choose evidence based strategies with participation of stakeholders Include all direct and indirect stake holders in decision making Refer & consult national plans Clarify policies and plans Undertake pilot project before starting the programme Develop quantifiable definitions of strategic activities Maintenance of permanency of vision and mission

Components of the system	Factors influencing sustainability	Strategies to improve sustainability
Management	Establishing accountability Studying feasibility before initiating strategies Establishing efficient administrative systems and structures Establishing personnel management systems	Improve transparency through frequent communications Effectively use available infrastructure Describe roles & responsibilities for personnel Institute appraisals Establish consensual decision making Regularise monitoring and participatory planning exercises Respond to consumer feed-back Avoid high staff turnover Institute career planning for personnel Enhance training of appropriate skills
Leadership	'Personality' of the leader Transparency in communications Technical skill High motivation Supervisory ability	Promote democratic leadership Phase out unsuccessful strategies Introduce mid course changes Avoid hidden agenda Enhance motivation of personnel Enhance interest of all stakeholders Decentralise operations and transfer responsibilities to disabled persons & their families

Components of the system	Factors influencing sustainability	Strategies to improve sustainability
Financial	Optimal use of resources Ensuring evidence based, cost effective and cost beneficial interventions Availability of financial resources Access to national governmental and non-governmental funds Ability to change according to needs of national & international economic situation Avoidance of over-funding beyond project's capability of assimilation	Make available multiple sources of funding Access governmental funds & community funds Designate income & expenditure to activities Institute cost efficiency and cost benefit analysis Avoid over-funding of projects
Interventions	Training Research Acceptable coverage and quality Regular monitoring and evaluation Creating awareness about the programme	Use of evidence based interventions Use appropriate technology suitable to local culture Training and updating intervention skills Undertaking research to upgrade interventions Aiming for maximum coverage with available funds at optimum quality Terminating unsuccessful strategies Monitoring regularly and making needed corrections

Components of the system	Factors influencing sustainability	Strategies to improve sustainability
		Evaluating periodically and making mid course changes in objectives Instituting structured and target related awareness building strategies
Phase out plan	Withdrawal of catalyst agency Technical & financial self sufficiency Attitude change in community Permanency of 'vision' & 'mission' Assimilation of policies by all stake holders Proven methods of interventions Rapport with community and clients Well established administrative systems	Develop time specified, area specific, sector specific withdrawal plan Improve community participation at all levels of programme including monitoring and evaluation Empower participation of disabled persons And their families in the project Encourage maximal use of volunteers from community Avoid mid course changes in 'vision' & 'mission'.

POINTS FOR DISCUSSION

1. **How would you define sustainability?**
2. **Can your CBR project become sustainable? How?**
3. **Can you identify any special strategies to achieve sustainability in your CBR programme?**
4. **What are the roles of donors, community and people with disabilities in improving sustainability of your CBR programme?**

10 COMMUNITY BASED REHABILITATION EVALUATION

WHY EVALUATION?

Evaluation is the only way to make rational choices between alternative practices, to validate improvements and to build a stable foundation for future practices. Apart from these factors, policies of private and government agencies now make approval of grants based on good planning and sound evaluation practices.

Differences between 'Research' and 'Evaluation'

	Research	Evaluation
Purpose	Theory building	Mission accomplishment
Outcome	To generalise conclusions	To apply conclusions to a programme
Value	To explain logic of an event	To assess worth of an activity
Concepts	Study of cause-effect relationships	Study of means-ends relationships
Method	Hypothesis testing	Assessment of goal attainment
Types of studies	Experimental research Applied research	Outcome evaluation Process evaluation

EVALUATION CYCLE

1. PROBLEM IDENTIFICATION
2. PLANNING
3. IMPLEMENTATION
4. PROCESS EVALUATION
5. OUTCOME EVALUATION
6. BACK TO PROBLEM IDENTIFICATION

What is 'Process Evaluation'?

Process evaluation provides information about the strategy as it is being implemented, so that strengths can be retained and weaknesses can be eliminated.

What is 'Outcome Evaluation'

Outcome evaluation ascertains to what extent goals of a programme have been achieved. It measures short-term outcomes and long-term outcomes (impact).

What are 'Indicators'?

They are summary measures of a population characteristic, used to measure progress with respect to programme targets. They can be 'direct indicators' or 'proxy indicators' that indirectly reflect progress of direct indicators. In rehabilitation, outcome indicators used in the past were mostly quantitative measures, which did not adequately measure quality of life factors that are usually intangible during a study. Indicators that elicit short-term outcomes and long-term outcomes (impact) are different from each other. Indicators are related to goals of the programme and methods used to achieve them. When choosing indicators during a study, it is useful to select some universal indicators that apply to programmes universally in the same category, and some programme specific indicators that apply only to the specific project. The former group of indicators facilitate comparisons between programmes, while the latter provides more programme specific information.

Examples of Indicators

Short-term outcome indicators: Utilisation of services, quality of care, access to services, improvements in mobility, activities of daily living skills (ADLS), domestic activities and so on.

Long-term outcome indicators: Change in community attitudes, change in self-esteem of disabled persons, change in economic status of disabled persons, participation in social relationship activities, participation in education and work, participation in civic and community life and so on.

{For further examples of indicators, refer Boyce W et al. CBR and Disability Indicators. Asia Pacific Disability Rehabilitation Journal 2001, Vol 12(1): 1-21; Wirz S, Thomas M. Evaluation of CBR Programmes: A Search for Appropriate Indicators. International Journal of Rehabilitation Research 2002, Vol 25 (3)}

STEPS OF EVALUATION

Step I	Clarify policies	Vision, Mission & Objectives
Step II	Relate activities to objectives	Objectives & Activities
Step III	Define outcome indicators in quantitative & qualitative terms	Develop tools to measure long-term & short-term outcome indicators
Step IV	Identify targets of achievement in a unit time	If targets are not already set, estimate a reasonable level of achievement
Step V	Identify sources of information for study	Programme documents, Interviews & Observations Develop tools
Step VI	Plan Methodology	Field work
Step VII	Record findings	Analysis
Step VIII	Interpret findings	Reporting
Step IX	Suggestions for change	

ANSWER THESE QUESTIONS BEFORE UNDERTAKING AN EVALUATION

1. What Do You Need To Know And Why?

- Needs and resources
- Relevance of 'vision', 'mission', their clarity and transparency at present.
- Efficiency of systems of administration and management.
- Short term effectiveness of interventions.
- Long term impact of interventions.
- Sustainability of financial, technical and personnel aspects of the programme.
- Community ownership of programme.

AREAS REQUIRED TO BE COVERED BY EVALUATION

- Relevance of the programme
- Effectiveness of interventions
- (Short term effectiveness and long term effectiveness-impact)
- Efficiency of systems of administration
- (Systems that maintain interventions and systems that maintain organisational functions)
- Sustainability of the programme
- Community ownership of the programme

2. WHAT INDICATORS ARE BEING USED, WHAT SOURCES OF INFORMATION ARE AVAILABLE, WHAT IS THE SAMPLE FOR THE STUDY?

Matrix for Designing Evaluation Methodology

Project elements	Outcome Indicators	Quantitative Measures	Qualitative Measures	Sources of Information	How to collect data
Vision/ mission	Long term (impact or long term outcome)	**How much?**	**How well?**	**From where?**	**What method?**
Objectives	Medium term (process and medium term outcome)				
Activities	Short term (process and short term outcome)				

- Define criteria for outcomes (Indicators)
- Identify what measuring instruments are most suitable for use

Usefulness of Quantitative Data

- Data are accurate.
- Gives broad picture of a large population.
- Identifies major differences in trends of a population.
- Useful for establishing baseline data.
- Useful to statistically establish cause-effect relationship.
- Data generated can be statistically generalised.

Usefulness of Qualitative Data

- Useful to identify amorphous data on change (qualitative variations of indicators) (Aims of qualitative research are to understand motivations and perceptions of clients and providers and how they impact on behaviour).
- Requires less time and funds to study.
- More effective than quantitative data with a skilled practitioner.

- More useful than quantitative data for organisational development and future planning.
- Qualitative data are useful only if a range of samples are chosen to represent all different groups and new clients are interviewed, until fresh responses stop occurring during serial interviews.
- Qualitative data are useful only if researcher bias is reduced to minimum and at least two researchers analyse data to reduce bias.
- Qualitative data are useful only if all samples give their opinion with equal ease.
- Qualitative data are useful only if researchers identify why some samples give deviant opinion from the majority.
- Qualitative data are useful only if researchers refer back to other similar research findings and theoretical interpretations.

Questions to be Answered Before Using A Tool

- What information are you looking for?
- Is there a need to collect this information and is the answer necessary for your plans?
- What questions need to be asked to collect this information and are they reliable and valid?
- Who will answer these questions and are they willing to answer them?
- Who will ask questions? Do they have skills to do it?
- Who will analyse results and make inferences?
- Is this exercise conducted at an affordable cost?

Types of Information

- Information that already exists in programme documents
- Information that requires to be generated anew
- Qualitative information
- Quantitative information
- Information collected by questionnaires
- Information collected by observation
- Information collected by interviews
- Information from key informants
- Information from groups
- Information from sample population
- Information from entire population

Examples of Quantitative Attitude Scales

A. Summated rating scales

Subjects need to respond to varying degrees of 'conviction' between two polar 'attitudes'

Example:

"Capital punishment is necessary"

Strongly agree/Agree/Undecided/Disagree/Strongly disagree
1 2 3 4 5

OR

Strongly agree/agree/disagree/strongly disagree
1 2 3 4

OR

Strongly agree ._._._._._._._._._._.Strongly disagree
1 2 3 4 5 6 7 8 9 10

They are scored attributing a value to each response, assuming that differences between responses are equal.

B. Thurstone type of scales

Multiple attitudinal judgements about an event are given quantitative values by a group of judges (Collect all attitudinal statements from a group of people, eliminate infrequent ones, assign quantitative values by consensus from the group of people, for each item)

Example:

"CBR helps disabled people in this district better than any other intervention here" 10 points

"Even though our CBR is not the best, I would still want this project" 8 points

"Even though benefits from CBR are very little, CBR workers and disabled persons get at least some benefits" 5 points

"Our CBR is actually a waste of time for all people concerned" 2 points

C. Cumulative scales

This consists of small list of attitudes, uni-dimensional in nature, measuring only one attribute.

Example:

"I would like to ask some questions about a disabled person who lives in your village"

1. Would you object to such a person living in your community?
2. Would you object to him working where you are employed?
3. Would you object to inviting him to your home socially?
4. Would you object to him marrying a member of your family?

Answer 'yes' to question 1 predicts 'yes' to 2, 3 and 4.

Answer 'No' to item 4 predicts 'no' to item 3, 2 and 1

Answer 'No' to item 1 and 'yes' to item 2 predicts 'yes' to item 3 and 4

Scoring can be 4 for strongest acceptance and 1 for strongest objection

Selection of Sample and Sample Size

- Sample size should be planned when study is planned.
- 'Sample size' is the approximate minimum number of persons that should be studied within a particular limit of cost and precision.
- A large sample size is required when a large number of uncontrolled variables are interacting unpredictably in the population studied, when total sample is to be divided into several sub-samples, because population is made up of wide range of characteristics and When differences in results are expected to be small.

A Rough Guide To Sample Size (N = Population, S = Sample Size)

N	*S*	*N*	*S*	*N*	*S*
10	10	200	132	1600	310
20	19	250	152	1800	317
30	28	300	169	2000	322
40	36	400	196	3000	341
50	44	500	217	4000	351
60	52	600	234	5000	357
70	59	700	248	7000	364
80	66	800	260	10000	370
90	73	1000	278	20000	377
100	80	1200	291	50000	381
150	108	1400	302	100000	384

3. How should one collect data?

Types of Evaluation

- **Historical studies:** To construct the past accurately and objectively in relation to a hypothesis and to maintain sequences.
- **Descriptive studies:** To describe the concerned situation accurately and factually.
- **Case studies:** To study factors such as background, current status and interrelationship of the index unit in its context - an individual in a group, an institution or a community.
- **Correlation studies:** To study cause-effect relationship of one variable factor over another constant factor.
- **Experimental research:** To study cause-effect relationship of factors by controlling context.
- **Action research:** To identify new methods to solve problems in programme execution.

Differences Between Experimental Research and Action Research

	Experimental research	Action research
Training requirement	Extensive training needed	Limited training needed
Goals	To develop theories that can be generalised and applied to large populations	To identify interventions that can improve programmes
Involvement of the research worker in the programme	Research worker understands the problem, but is not involved	Research worker is usually selected from the programme personnel
Methodology	Controlled to avoid influences of external variables and sample is selected randomly to represent entire population	Less attention is paid to controlling external variables and sampling; study is usually conducted in natural setting
Hypothesis	Highly specific hypothesis developed with its operational definitions	Statement of problems usually serves the purpose instead of hypothesis
Review of literature	Primary sources need to be reviewed extensively	Mostly secondary sources and few primary sources are reviewed

Types Of Surveys

(Select indicators, select questions, choose appropriate methods to collect answers, choose appropriate sample, train data collectors, pilot test tools, collect data, analyse data, interpret data)

A. Survey of records:

- Records are non-reactive, inexpensive and provide trend lines and base-line data.
- They are often inaccurate, incomplete and not comparable between different years because they are recorded differently during different years.
- They give only factual data and not attitudes.

B. Mailed questionnaires:

- It is inexpensive, easily prepared, self-administered and can be made anonymous.
- But few people respond
- They may be answered by people who are not are not relevant to the study.
- Sample can be skewed.

(Structured, semi-structured, open-ended, key informants)

C. Telephone interviews:

- It is inexpensive and has flexibility.
- In developing countries, penetration of telephones may be low.
- It provides extended geographical coverage.
- Respondents are comfortable when they are in their own setting.
- Telephone interviews do not provide clues that the interviewer gains from observing facial expressions.

(Structured, semi-structured, open-ended, key informants)

D. Group interviews:

- Group interviews are more economical.
- Consensus formation and conformity occur, eliminating individual differences.
- It can be used to identify group interaction patterns, brain-storming and to develop group loyalty.
- Opinions however polarise and sometimes are implanted by powerful subgroups.

(Participatory Rapid Assessment (PRA)—Qualitative, open-ended, group interview method. Cost-effective, participatory, quick, comprehensive information.)

(Structured, semi-structured, open-ended, key informants)

E. Individual interviews:

- It is personalised, allows great depth, flexibility and perception of facial expressions.
- It is however time-consuming, annoys some respondents and can be manipulated by respondents.
- It requires skilled interviewers and is difficult to summarise.

(Structured, semi-structured, open-ended, key informants)

F. Screening:

- It is the process of identification of people at risk within a target population.
- Screening is potentially expensive and could be useless unless well-defined (sensitive) and coverage is adequate.
- Screening is carried out using screening tests.

4. What are the assumptions made during a study?

A. Validity of Study: Internal validity

Is the cause-effect relationship genuine or spurious?

In other words, has the independent variable produced a change in the dependent variable?

Such changes can appear to occur falsely:

- Due to improvement in performance of subjects with repetition of tests many times.
- Due to mid-course changes in methods of collecting data.
- Due to bias in sample chosen, that does not represent the total population.
- Due to interplay of multiple factors on the dependent variable rather than the one studied.

Common sources of error in internal validity:

- **Halo effect:** Impressions or opinions from celebrities in early stages of study influence results. Unclear definitions of variables studied results in more impressionistic results.
- **Rating errors:** 'Over-rater error' rates subjects favourably. 'Under-rater error' rates subjects unfavourably. 'Central tendency error' rates subjects towards middle of the scale.
- **Hawthorne effect:** Because of novelty, awareness and artificial environment during the study, the selected people for the study perform better than others who are not selected.
- **Self-fulfilling prophecy:** Researchers who have preconceived opinions collect data to substantiate their opinions leaving out data that contradict their beliefs.
- **Placebo effect:** Even neutral interventions will give some non-specific effects as if it is an active intervention.

- **Typical case studies:** Typical case studies are usually quite atypical.
- **Post-hoc error:** Many random associations are mistaken for cause-effect relationships.
- **Use of inappropriate tools and methods:** Inappropriate use of tools developed for other studies may give spurious results.
- **Reactive effects: S**ubjects try to do their best during the study period. During the study subjects try to behave themselves in a role they feel they are expected to be in. With practice subjects perform better. Subjects usually endorse positive statements more than negative statements. Subjects endorse socially acceptable statements more than socially unacceptable statements. Subjects' responses vary according to interviewer's age, sex, behaviour, dress and so on.
- **Period of study:** Inferences about long-term effects from a short-term study can be inappropriate.
- **Sample size:** Use of too small a sample size can give invalid results. (Obvious effects require only small sample sizes, while less obvious effects will require a larger sample.)
- **Reliability:** Measurements used do not have consistency between tests.

B. Validity of Study: External validity

It answers whether results can be applied to situations outside the study. They cannot be generalised if:

- Results can only be applied to the sample because sample is unique to the study.
- Results are only an effect of peculiar behaviour of the sample during the study and do not get repeated later.

C. Reliability

It answers whether the tool used can elicit the same scores when used on the same client at different settings or at different periods.

D. Sensitivity

Sensitivity is the proportion of positives detected by a tool used for the study. Higher 'false negatives' suggests lesser sensitivity.

E. Specificity

Specificity is the proportion of negatives detected correctly by a tool used in the study. Higher 'false positives' suggests lower specificity.

5. What are the definitions of terms used?
6. What are the limitations of the study?

What are the common mistakes during a study?

- Defining questions to be studied during evaluation very ambiguously.
- Undertaking evaluation without literature review related to the study.
- Selecting questions that are too broad without clear boundaries.
- Collecting data without a well-defined purpose.
- Collecting batches of pre-existing data and trying to fit questions to collected data.
- Failure to recognise limitations of the study.
- Failure to consider how to analyse data to find meaningful information.
- Collecting facts without synthesising and generalising them.
- Inability to quantify collected data.
- Collecting data according to conveniences of access rather than by sampling.
- Using questionnaires that are not pre-tested.
- Using questionnaires that contain too many questions.
- Using self-reporting questionnaires that are badly printed.
- Allowing personal bias to influence evaluation.
- Interpreting based on biased interviews.
- Expecting to get too many answers from brief interviews.
- Asking questions that respondents do not know how to answer.
- Observing the sample while everyone is prepared to put out his or her best.
- Interpreting random associations as cause-effect relationships.
- Failure to make assumptions explicit so that results can be understood in terms of these assumptions.

TIPS TO AVOID BIAS IN EVALUATION

- Avoid leading questions.
- Use representative sample.
- Avoid powerful key informants.
- Do not feel reluctant to ask uncomfortable questions.
- Listen to every aspect of the answer rather than selective aspects.
- Do not exhibit annoyance during interviews.
- Avoid promoting positive answers.
- Train evaluators to use the questionnaire in the same manner with different clients.
- Collect same information from different groups.

4. WHO WILL BENEFIT FROM ANALYSING PROBLEMS AND IDENTIFYING SOLUTIONS?

CLASSIFICATION OF RESEARCH CONSTITUENCIES

Research Constituencies	*Examples of sources from which to draw sample*
Consumers of Rehabilitation Those directly affected by disability and to whose interests the study is planned or end-users of the study	Individuals with disability, family members, individuals without disabilities who utilise rehabilitation technology, agencies that are customers of rehabilitation, community members contributing to the programme, employers who provide jobs for disabled individuals, other community service organisations, public service enterprises.
Practitioners and Providers Professionals, paraprofessionals and organisations that make use of research in rehabilitation for related services.	Individual rehabilitation professionals and paraprofessionals, allied rehabilitation personnel, community-based service providers, employment programs personnel.

Research Constituencies	*Examples of sources from which to draw sample*
Advocates of disability issues Representatives of people with disability, individuals, public and private organisations and other entities promoting or supporting disability or having interest in research, fiscal issues or public policy	Individual advocates for persons with disabilities, advocacy organisations, national councils on disability, coalition of citizens with disabilities, accrediting and certifying bodies, cultural and special interest groups, public policy leaders and elected officials, public rehabilitation agencies and staff, bureaucrats and donors.
Those involved in research and advocacy Those who build upon information, knowledge, and research to solve specialised problems, develop devices and practices, access knowledge and apply to other disability needs.	Individual researchers, research confederations, professional associations, product and service developers, rehabilitation educators.

5. Who Will Use Information From the Evaluation to Make Decisions?

6. How Much Funds are Available for the Evaluation?

Points for Discussion:

1. **What answers will you look for if you were to evaluate your CBR project at this time?**
2. **How will you collect information for your study?**
3. **What mistakes do evaluators commonly make while collecting information?**

11 COMMUNITY BASED REHABILITATION TRAINING OF PERSONNEL FOR CBR

The need for a new cadre of worker for rehabilitation, namely community rehabilitation worker (CRW), was advocated by World Health Organisation in 1981. The major difference cited between other forms of rehabilitation and CBR was that in the latter, the needs of people with disabilities were met in their own environment, involving family members and community. More or less at the same time, it was also stated that highly trained health professionals were not suitable to address the magnitude of problems in rural health care services. It was because their training was costly, they were accustomed to working in technologically superior settings, and they seldom functioned well outside places with good infrastructure. Consequently, there was significant advantage in training community level workers to provide basic home-based therapy on a day-to-day basis. Such training required a basic understanding of principles of anatomy, physiology and pathology of disabilities. More importantly, the workers needed significant training in using a functional approach to technical assessment and management of disabilities, with particular emphasis on problem solving, documentation, realistic goal setting and an understanding of simple progression of rehabilitation programmes for the common disabilities which they encountered. After training, these workers needed to continue their learning with 'expert' therapists who acted as trainers. These 'experts' would provide advice on a regular basis and review complex cases, meanwhile contributing to continuing education of mid-level workers.

Manpower model of National Institute of Mental Retardation, Canada: For mental retardation in CBR

Cadre	Level	Period of Training	Percentage of tasks managed
Professional	Level I	More than 2 years	20%
Professional	Level II	More than 2 years	20%
Non-professional	Level III	Less than 2 Years	80%
Non-professional	Level IV	Less than 2 Years	80%

Types of Tasks in CBR

1. Technical Tasks (examples)

Disability assessment, therapeutic interventions, family counselling, counselling for rehabilitation, etc.

2. Programme Management (examples)

Community organisation, community development, public education, programme supervision, advocacy, income generation for the family, organisation of self-help groups, record keeping, etc.

Critical Issues to be Considered in Training CBR Personnel

The beginning of the new millennium coincides with the beginning of evidence based practice in CBR. Unlike in small programmes, sole reliance on past experience will be insufficient to initiate, maintain and achieve the goals of large programmes. Hence great importance will be given in future to policy development, planning and monitoring. Good systems, efficient structures and tangible results will become preconditions for funding large projects. Pressure to follow internationally accepted good practice codes would become a necessity. On the whole, CBR will consolidate into a better defined, more accepted framework of development for people with disabilities, within which wide contextual flexibility will be permitted for each programme's structure and systems.

These changes in approaches are likely to make programming a crucial aspect of any new initiatives in CBR. Planning for programmes in the community is very different from planning for an institution in the same setting. Communities usually do not provide ready-made structures and systems for programme implementation unlike institutions. Hence, programmes have to be developed from grass-roots in a 'bottom-up' manner by organising the community to evolve collective and consensual strategies using a participatory process. In institutions, members can be coerced to follow top-down strategies, but in community based programmes members have to be persuaded to accept strategies before they follow them. Predictability and external control in these programmes are relatively more difficult to achieve, unlike in institutions. These changes in approach will have implications for training of CBR personnel.

Over the years, CBR programmes have evolved their own models of personnel structures, which are variations of models given below.

The assumptions here are:

1) Trained professionals are not adequately available for CBR programmes

2) Non-professionals can complete 80% of tasks in a CBR programme

3) Cost of using non-professionals is low

COMMON MANPOWER MODELS PRACTISED IN CBR

Model I		Model II	
CBR Manager	Administrator	CBR Manager	Administrator
Professional	Trainer/ Professional	Professional	Trainer/ Professional
Mid Level Rehabilitation worker (MLRW)	Multipurpose worker / Trainer / supervisor of CBRW	1. Therapy Assistant 2. CBR Supervisor	1. Technical /Trainer of CRW 2. programme Management/ Trainer of CRW
CBR Worker	Multipurpose/ Low depth/ interacts with family	CBR Worker	Multipurpose/ Low depth/ interacts with family

Principles of Training CBR Personnel

Many CBR trainers opine that there are several distinct principles that must be adopted in providing training to CBR personnel.

1. An adult learning approach to presentation of materials must be used rather than the traditional pedagogical approach.
2. Interactive or experiential learning is much more successful and promotes thinking and reasoning rather than rote learning.
3. A functional approach to assessment and intervention is essential, rather than the traditional 'medical model' to diagnosis and treatment. A functional approach is more meaningful to the client and caregivers and provides greater motivation to improve, as clients can see that the interventions affect their ability to perform normal activities of daily living.
4. Theoretical sessions must be interspersed with practical sessions whereby participants can practise their skills and acquisition of knowledge on each other, before exposure to clients with disabilities.

5. Fieldwork practice sessions are essential, from the very beginning of any training programme, so that participants can put into practice what they have learned in the 'classroom'.
6. Regular review of knowledge and skills, with concurrent feedback is highly recommended.
7. Level and complexity of knowledge and skills presentation must be tailored to the needs and educational standards of the participants.
8. Training in documentation is essential. It provides an objective baseline assessment for the functional status of the client, from which realistic, measurable treatment goals can be established. Therapists can therefore evaluate efficacy of interventions and progression of therapy. It is essential that measurable outcomes be introduced. Such documentation can also be of value to CBR co-ordinators, in that they can measure effectiveness of their CBR programmes; they can also discover deficits in CBR workers' knowledge and abilities, thereby identifying continuing education needs.

There are many debates around the issue of whether community level workers should be multi-skilled in all areas of CBR or whether there is value in training different types of community level workers; that is, therapy workers, community workers, etc. No one system is appropriate for all CBR programmes. It may be appropriate, for example, to have separate 'therapy workers' in projects that have a large number of clients or a large area of coverage and where there is significant community development work to be done. In another project it may be more appropriate for CBR workers to incorporate all aspects of community based rehabilitation in their work, such as therapy, community involvement, income generation, etc. If the former model is adopted, it is essential to define the line of communication between levels, so that all workers focus on the common goal - that is, the person with disability who needs to gain maximum opportunity to become an active and equal member of the community

Training of CBR Managers

While training of lower levels of CBR personnel has been evolving over the years, the training of CBR managers is still at a trial-and-error stage. Many CBR programmes have tended to follow the PHC model where an interventionist (medical doctor, therapist, or special educator) is also the manager in charge of programme administration. This leads to dilution of efficiency of interventionists, because they are used in areas where they are not skilled. As a result it also reduces efficiency of the programme. For programmes to be efficient, they must have clear systems and well-defined roles for their personnel. The responsibility of managing and administering programmes should ideally vest with managers who have the necessary skills.

As in the training of other cadres of workers, training courses for CBR managers also tend to be loaded with theoretical knowledge, emphasis on institutional and service delivery approaches, with less attention to creativity, problem solving, aspects of community development and community organisation. The shift to a social and developmental approach in CBR is not sufficiently reflected in training programmes for CBR personnel, especially managers.

Another aspect that is largely missing in training of managers, is the systematic, result-orientated planning process that is crucial to success of CBR programmes. Many CBR programmes are carried out by voluntary organisations in non-governmental (NGO) sector. A close look at some of these programmes shows that they originated as a set of activities without clear goals or long term plans. Some programmes were started because of availability of designated funds for that particular activity, at that point in time. With shifts in donor priorities, activities of some of these organisations changed accordingly to avail of the funds. These programmes often did not have monitoring and evaluation systems, nor did they define their outcomes or attempt to measure them. Instead, they repeated a set of activities year after year, with anecdotal reports from their clients, to justify why they continued them. Such activities were donor dependent, cost-intensive, seldom successful, and rarely sustained if the donor withdrew support. They could become counterproductive to local community's efforts to develop a more appropriate, grass-root led rehabilitation service. Consumer satisfaction in these programmes was also limited, as client needs were rarely taken into account.

It is necessary to have clear goals and a set of related activities for a programme to be successful. The sequence of programme planning should include a situation analysis, including needs and resources; definition of vision, mission and objectives; detailing of activities, outcomes and indicators. Training managers in this process is crucial in developing effective and efficient programmes. Hence, managers' training programmes must have need-based and well-planned curricula that originate from task analysis of responsibilities expected of them. Training to plan and develop efficient management systems also is required.

CURRICULUM DEVELOPMENT

LEVELS	CURRICULUM FOR	ESSENTIAL	DESIRABLE	UNDESIRABLE
I CBR Manager	Manager's training	**	**	**
II Professional	Professional's training	**	**	**
III Mid-level Rehab worker (CBR Supervisor / Co-ordinator & Therapy assistant)	MLRWs & CBR supervisor / co-ordinator's training. Therapy assistant's training	**	**	**
I V CBR worker	CBR worker's training	1. Home based interventions 2. Community & family organisation 3. Teaching skills	1. Prevention 2. Awareness programmes 3.Government. schemes	1. Institution based interventions
Family of the Disabled Person	Family member's training for home based intervention	**	**	**

Curriculum development is about 'what to teach and how to teach'. It is procedural in nature. Students' needs are analysed and learning goals and objectives are identified. The syllabus is a document that states what is required to be learnt. Syllabus design takes care of selecting, grading and sequencing content of the course.

Components of a curriculum are those activities to be carried out by trainees in order to generate essential knowledge to perform the desired work, at a pre-designated optimum level of efficiency. Qualifying tests estimate if a trainee has achieved the essential level of knowledge. Desirable components of a curriculum are those skills

that are useful to trainees to carry out their work in a better manner than the minimum required level. Qualifying tests assess the achievement of the trainee and grade him according to his level of proficiency. Undesirable components are those skills that if learned, can have a detrimental effect on the efficiency of a trainee in his work situation. Qualifying tests give negative points if these components are learned.

High turnover of staff can occur as a result of over training. It will help to do a task analysis to understand the precise nature of tasks expected of trainees in their normal working situation. The desired level of training is one that produces optimum level of effectiveness at an affordable cost. The desired level can also be considered as one at which effectiveness tends to plateau out in spite of increasing costs of training.

Most existing CBR workers' courses have derived out of institutional rehabilitation courses. The curricula in these cases were developed based on institutional teaching experience and they were best suited for trainees who opted to work in institutions. They were loaded with training in technical skills and lacked training in skills that were essential to have a successful programme in the community, namely, the ability to be innovative and organising families and communities for CBR work. As a result, CBR workers functioned as institutional extension workers, rather than as community workers. The disparity between their manner of work and their expected role in CBR often led to conflicts, especially in initiating community participation for CBR. Such workers were often reluctant to transfer management responsibilities from caregivers to clients. In order to function efficiently in a CBR setting, CBR workers' training courses need to have appropriate, independent, stand-alone curricula, rather than an adapted institutional course.

Some Examples of Training Manuals For Use in Community Based Rehabilitation

1. Portage Guide to Early Education (PGEE): Low cost home based training for mentally retarded children between birth and six years.
2. Distance Training Package (DTP) (Bangladesh): Training materials for the parents of mentally retarded children to be used at home.
3. Zimcare Trust Training Packages (Zimbabwe): Packages for training of mentally retarded children.
4. WHO Training Manual (WHO): For all disabilities, for community workers.
5. Disabled Village Children: Manual for Health Workers, Rehabilitation Workers and Families. (Mexico): For all disabilities.
6. Simple Aids for Daily Living (AHRTAG-LONDON).

7. Manuals from the CBR Development and Training Centre, Solo, Indonesia. For all disabilities
8. Handicap International training manuals. For physical disability and chronic disease.
9. Spastics Society of Eastern India. Booklets for trainees and for parents. Mainly for children with cerebral palsy.
10. Helpful Steps. Training materials of the Guyana CBR programme, with videos.

These are only few examples. Many more manuals are now available to choose an appropriate one according to one's own requirements.

DIFFERENCES BETWEEN INSTITUTIONAL AND CBR TRAINING

Areas of differences	Institution	CBR
Duration & location of training	4 years degree - 'Institutionally trained'	3 months to 1 year - 'Locally trained'
Type of training	Trained to manage acute, complex cases, and in the use of sophisticated technology	Trained to teach family and clients to cope with consequences of disability within the community settings, using the available resources
Extent of training	Interventions limited to skills training for clients	Interventions to fulfil the needs of clients regarding daily living activities in their home environment
Goal of the training	Interventions to discharge patient quickly from hospital	Interventions to prepare re-entry of client to his home / community
Setting for the intervention	Interventions take place in institutions	Interventions take place in client's home

Areas of differences	Institution	CBR
Resources needed for the intervention	Solutions are based on high technology equipment	Solutions are based on resources from community
Knowledge base of the trainees	Users of manuals are highly trained and know medical terminology describing the state of the art technology	Users of manuals are lay people, poorly trained and unfamiliar with medical terminology
Language of the manuals	Universal language can be used to write the manuals	Manuals have to be written in context of local culture, tradition and dialect
Type of clients	Small number of disabled persons who require sophisticated technology for their rehabilitation	Majority of disabled persons who require only simple techniques for their rehabilitation

POINTS FOR DISCUSSION

1. **What are the training needs of different levels of personnel in your CBR programme?**
2. **What training materials are available to you?**
3. **What are your suggestions to improve training of your CBR personnel and make it more appropriate to your CBR programme?**

12 COMMUNITY BASED REHABILITATION MANAGING CHANGE

Why change?

To remain efficient and effective, organisations have to adopt changes. A majority of organisations initially resist changes, and as a result they face a competitive disadvantage. Eventually they find that they have to change to remain competitive. As an organisation grows, change is inevitable, and if change is not planned carefully, the organisation, be it large or small, disintegrates soon.

Planning Change

Successful change programmes need a high level of planning. For good planning, goals should be clear and focussed, and should be expressed as 'vision' and 'mission' statements in one or two sentences. To be successful in change, stakeholders' opinions should be considered in great detail. Roughly 20% of the activities account for 80% of outcomes in most cases.

- Prioritise change in key areas and then focus attention to the rest.
- Realistically estimate the complexity of change, such as expected outcomes, who will be affected directly or indirectly by change and so on.
- Introduce change in stages, because different changes need different time-scales.

Implementing Change

A change plan is good, only if it can be implemented. Communicating about change is vital, and people need to be drawn into the change process as quickly as possible, even if they were not involved in planning.

- Communicate change plans at the earliest to all people affected by change.
- Start with a concise vision statement about what could occur after change and follow by presenting the total picture of the process.
- Do not conceal bad news if there are any. But give explanations about them and explain why it is unavoidable.

Assigning Responsibility for Change

Change plans call for leadership and for inspired followers.

- Assign active roles in change plans to people at different levels.

List changes to be achieved, decide who should execute them, draw up specific tasks for each person, discuss plans with each person and get feed-back about progress in implementation schedules regularly.

Assessing change-management skills

Evaluate how well you manage change by responding to the following statements, marking options closest to your experience.

(Options: 1 = Never, 2 = Occasionally, 3 = Frequently, 4 = Always)

I try to anticipate and lead change within my organisation	1	2	3	4
I look for opportunities for radical as well as continuous change	1	2	3	4
I like to be different and seek productive ways of creating a difference	1	2	3	4
I like an open minded approach towards new ideas and possibilities	1	2	3	4
I keep my change philosophy simple and concise	1	2	3	4
I break change plans down into manageable components	1	2	3	4
I consult widely in the process of deciding on strategy and action	1	2	3	4
I obtain people's agreement to actions demanded of them	1	2	3	4
I use and develop teams as basic units of change management	1	2	3	4
I plan well ahead for long-term pay-offs of change	1	2	3	4
I am careful not to create over-optimistic or over-pessimistic expectations	1	2	3	4

I seize opportunities to reward and encourage successful change	1	2	3	4
I make sure that everybody knows the answer to what is in it for them	1	2	3	4
I use well designed pilots and experiments to test my change plans	1	2	3	4
I share relevant information with colleagues and juniors	1	2	3	4
I work closely with like-minded people who are keen to change	1	2	3	4
My own behaviour is flexible and adaptable to changing needs	1	2	3	4
I encourage people to speak their minds openly and to air their concerns	1	2	3	4
I also use quantitative measurements to assess results that I want	1	2	3	4
I review and revise the assumptions that underlie change plans	1	2	3	4
I keep people up to date with change through training	1	2	3	4
I start the next change project as the previous one draws to a close	1	2	3	4
TOTAL SCORE IN EACH COLUMN				
GRAND TOTAL SCORE				

INTERPRETATION OF SCORES:

22- 44 You are resisting change or unsure of its potential benefits, learn to plan for change

45- 65 You understand the need for change, you however must develop skills to achieve it successfully

66-88 You are a skilled agent of change, so keep planning ahead

13 COMMUNITY BASED REHABILITATION DECENTRALISATION AND DELEGATION OF AUTHORITY

DEFINITION

'Decentralisation' is the process of delegating decision-making authority to lower units of the organisation.

'Departmentation' is the process of forming groups in the organisation to have small functional units of people with similar tasks. It is not synonymous with decentralisation.

'Geographic dispersion' is the process of subdividing the organisation into many geographically separate units and is also not synonymous with decentralisation.

STEPS IN DELEGATION OF AUTHORITY

Process	Assign tasks	Define activities along with defined outcomes
	Delegate authority	Give full authority to decide with regard to the delegated task on behalf of the higher authority
	Creation of obligation	Once tasks are delegated subordinate agrees to perform to the required standards
	Parity of authority and responsibility	Delegated authority should be effective enough to carry out the delegated task
	Absoluteness of accountability	Reporting relationship with the superior authority is never delegated to another person
	Unity of command	At any given situation a subordinate reports to only one superior authority and is accountable to only one person

Conditions for effective delegation	Differentiation of organisational structure and reporting channels	Undifferentiated organisations with poor reporting channels are led by multiple leaders and subordinates, and follow the lead of the most forceful person rather than the desirable person
	Discourage by-passing intermediate reporting authorities	The highest level of authority should be aware of activities of the organisation through observation and contact. Yet by-passing intermediate authorities is disadvantageous to the organisation
	Selection of people for delegation of tasks	Even though some subordinates are less skilled and knowledgeable, it is preferable to choose people who can take full responsibility for their acts
	Establishment of review and control systems	Good control through periodic reviews and mid-course changes are advantageous

Barriers to Delegation from People in Authority

1. Tendency of people in authority to be preoccupied with details of work rather than to lead.
2. Workaholics delegate poorly.
3. Tendency of people in authority to give attention to minute details rather than major issues reduces effectiveness of delegation.
4. Tendency of people in authority to fear failure.
5. Tendency of people in authority to distrust others.
6. Easy access to information due to the use of electronic communication systems reduces need to delegate.

Indicators of Efficiency of Delegation

1. Greater the frequency of decisions made at the lower levels of organisation, greater the decentralisation and delegation.

2. Broader the scope of decisions made at lower levels of the organisation, greater the decentralisation and delegation.
3. Lesser the number of approvals required before a decision is made at lower levels of organisation, greater the delegation and decentralisation.

Advantages of decentralisation

1. Decentralisation allows growth of professional managers.
2. Response time is shortened in making decisions.
3. Available management skills are fully utilised.
4. Decentralisation promotes competitiveness.
5. Decentralisation divides organisation into small units that are easy for people to identify with.

Advantages of centralisation

1. Centralisation allows strong leadership at the top.
2. Decisions made in centralised organisations are more consistent over time unless the leader is changed.
3. Centralised organisations spend less on management costs.
4. Centralised organisations have less duplication and overlap.
5. Confidentiality of aspects can be better maintained in centralised organisations.

When should an organisation go for decentralisation?

1. When the organisation becomes too large in size to make it difficult to continue as a centralised organisation.
2. When people in the organisation have enough capacity to take responsibility and authority.
3. When the top-level management is experienced and competent.
4. When goals of the organisation have become stable over a period of time.
5. When organisational goals fit well into personal goals of individuals of the organisation.
6. When geographic dispersion of units makes it mandatory for the organisation to decentralise.

Issues related to leadership and power are highly culture dependent. Practices that are appropriate in one culture may be viewed as inappropriate in another culture. "Leadership is the art of giving directions, while managing is the art of getting things done on a day to day basis".

Types of Leader

1. Authoritarian leader.
2. Paternalistic leader.
3. Salesman approach to leadership.
4. Most liked person approach to leadership.

Qualities of the Leader

1. Commitment to what they are doing.
2. Ethics and honesty.
3. Positive outlook in solving problems.
4. Confidence in self and organisation.
5. Trust in people.
6. Mistrust of unaccountable institutions.
7. Ability to listen to others.
8. Diplomacy in difficult situations.
9. Experience in recruiting good subordinates.
10. Good ability to organise own skills.
11. Good skills of goal setting.
12. Ability to use past experience and knowledge.
13. Ability to build team spirit.
14. Ability to command in difficult situations.
15. Ability to plan and decide strategies.
16. Good participatory capabilities.

Types of power exercised by leaders

1. Reward power.
2. Punishment power.
3. Expert power.
4. Power of position.
5. Charismatic power.

Needs felt by leaders during their assignment

1. Need for inclusion: Need to include others in own group and to be included by others in their groups.
2. Need for control: Need to control others and to be controlled by others.
3. Need for affection: Need to express affection to others and to receive affection from others.

Participatory Group Decision-Making

People accept their own decisions better than others do. Because of this reason decisions made by a group are more acceptable to all its members than decisions thrust on them by a leader. Group decision-making process involves participation of all group members. The quality of decisions by a group is usually better than ones made by the leader without consulting. Some leaders however, misuse participatory decision-making processes by taking decisions before the group process begins. They subsequently coerce group members to accept their decisions, without debates. The skills of the leader in initiating high level participation and focusing the direction of discussions are critical to success of the participatory process.

Leadership Skills

1. Ability to state a problem in a way the group does not become uncomfortable about and be able to approach the issue constructively.
2. Ability to give essential facts and clarity to the issue without giving suggestions.
3. Ability to get all people to participate.
4. Ability to accurately restate expressed ideas.
5. Ability to initiate problem solving behaviour by asking questions.
6. Ability to precisely summarise proceedings.

Common styles of leadership

1. Autocratic functioning.
2. Democratic functioning.
3. Anarchic functioning.

Points for discussion

1. **Is there a need for decentralisation in your CBR programme? Explain why?**
2. **What is the style of leadership in your organisation? How does this style affect your programme?**

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